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THE UNIVERSITY OF ALBERTA

THE REPORTED QUALITY OF LIFE OF SELECTED HOME HEMODIALYSIS PATIENTS

BY

(C) ANITA E. MOLZAHN

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH IN
PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA

SPRING 1986

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ISBN 0-315-30126-0

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DEGREE: Master of Nursing

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "The Reported Quality of Life of Selected Home Hemodialysis Patients" submitted by Anita E. Molzahn in partial fulfillment of the requirements for the degree of Master of Nursing.

June F. Kikuchi

(Supervisor)

Helen Simmons

John B Dossetor

DEDICATION

This thesis is dedicated to my husband, Nigel Scott. His knowledge and understanding of quality of life has grown, as has mine, in the preparation of this work.

The Reported Quality of Life of Selected Home Hemodialysis Patients

Abstract

Concern regarding the quality of life of patients with renal failure has increased since improved technologies and treatments have extended the lives of these patients. The purpose of the present study was to describe the reported quality of life of selected home hemodialysis patients with renal failure, in light of the Aristotelian-Thomistic philosophical theory of the good life, as interpreted by Mortimer Adler (1965, 1970, 1971, 1981, 1984).

For the purpose of the study, quality of life was defined as the good life or happiness in the ethical sense. In order to attain happiness, Adler (1970, 1971, 1981, 1984) states that every human being requires seven types of real goods: goods of the body, goods of the mind, goods of character, goods of personal association, economic goods, social goods, and political goods. These goods must be possessed and enjoyed in the right order and proportion, and appropriate means must be used to attain them, if the ultimate good of happiness is to be attained.

The following research questions were answered in the study: What types of real goods do selected home hemodialysis patients possess? Of what types of real goods are the patients privated? What instrumental means are involved in the acquisition of each type of real good? Of what instrumental means are the patients privated? What is the importance placed by the patients on each type of real good? What is the proportion of time spent by the patients in attaining and enjoying each type of real good? Semi-structured interviews, using an interview guide, and card sort tasks were conducted. Ten home hemodialysis patients were interviewed weekly in a private location. Two patients were interviewed on three occasions, seven on two occasions, and one on one occasion.

Content analysis of the data was carried out in light of the Aristotelian-

Thomistic philosophical theory of the good life. Categories and subcategories relating to the patients' possession or privation of the real goods and instrumental means to the real goods were established. The patients' statements about their present quality of life were segmented into analytical units, according to the established unit of analysis, and distributed over the established categories and subcategories of possession and privation of the real goods and instrumental means. The major categories of real goods were goods of the body, goods of the mind, goods of character, goods of personal association, social goods, political goods, and economic goods. The major categories of instrumental means were physiological, mental, social, economic, and environmental.

The following conclusions were based on the investigator's interpretation of the patient's reports, in light of the Aristotelian-Thomistic philosophical theory of the good life, and a few observations made by the investigator. It was concluded that at least half of the patients suffered some privation of the following types of real goods: some of the goods of the body (health and vigor), some of the goods of the mind (spirituality and pleasurable feelings), a political good (freedom of action), and an economic good (free time). Most of the patients possessed the remaining types of real goods.

The most common instrumental means that the patients seemed to possess included a mental means (attitudes and approaches) and a social means (receiving help). The means, of which some of the patients seemed to be privated, included some of the physiological means (rest and sleep, and state of health), the economic means (wealth, work, and free time), and environmental means. It appeared from the patients' reports that some instrumental means that seemed to be adequate, in that they resulted in the attainment of a real good, were inadequate in terms of attaining a good life. Such means included dialysis treatment, medications, and work.

In relation to the importance of the real goods to the patients, it appeared that goods of personal association were of greatest importance and the external goods (social, political, and economic goods) were of least importance. The patients did not necessarily spend the most time in attaining and enjoying the real goods that were of greatest importance to them. Generally, they seemed to spend the most time in attaining and enjoying goods of personal association and goods of the mind.

ACKNOWLEDGMENTS

I gratefully acknowledge the help and support of the thesis committee. Dr. June Kikuchi, as chairman, provided ongoing guidance and support. In particular, her assistance in conceptualizing quality of life and in developing the categorization scheme was invaluable. Dr. Helen Simmons was able to provide insight into philosophical principles and questions and helped me to clarify the definitions and aspects of the conceptualization. Dr. John Dossetor posed clinical questions that led to the development of the research proposal.

The support and encouragement of my husband, family, colleagues, and friends were invaluable. I am very grateful to the ten patients who so freely gave of their time and openly responded to my questions. As well, I am appreciative of the cooperation I received, in the conduct of my study, from the medical, nursing, and administrative staff of the institution in which the study was conducted.

Last but not least, I gratefully acknowledge the financial support provided by the National Health and Research Development Program (NHRDP), Health and Welfare Canada, and the Alberta Foundation for Nursing Research (AFNR). It should be noted that these funding bodies (AFNR, NHRDP) do not necessarily support any views or findings presented in this thesis.

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I. INTRODUCTION

Background of the Problem

Since the introduction of chronic hemodialysis in 1962, the lives of many individuals with end stage renal disease have been prolonged. Initially, resources were very limited and only a few medically and socially acceptable candidates were selected for treatment (Fox & Swazey, 1974). With increasing technological, and human and monetary resources, essentially all persons requiring dialysis treatment are now being offered it.

Hemodialysis is a treatment whereby blood is passed through an artificial kidney in order to remove wastes, toxins, and excess fluid. Two needles are inserted into a surgically created blood access and are used for the removal and return of blood. The treatment generally takes four to six hours to complete and is carried out three times weekly. It may be conducted in the hospital setting or at home with the assistance of a family member or paid helper. The individual with renal failure and receiving dialysis treatment must adhere to a strict dietary and medical regimen. Although dialysis patients are prone to develop a number of secondary complications, their life expectancies have increased dramatically.

Statistics obtained from the Canadian Renal Failure Register (1982) indicate that in Canada, at the end of 1981, 5719 patients were receiving care for chronic renal failure (p. 7). Of these, 3354 were receiving some form of dialysis treatment; the remainder had had renal transplants. New patients had entered treatment programs for end stage renal failure at a rate of 48.2 per million of population. Of these new patients, 25 % were over 65 years of age. It is also of interest that the second most common cause of renal failure (after glomerulonephritis), accounting for 16 % of the affected population, was found to be diabetes. Both the elderly individual and the diabetic were at one time denied dialysis treatment (Fox & Swazey, 1974). Today, however, quality of life issues surround treatment of these groups of people (Annas, 1980; Kart, 1980), and health care workers have become concerned about, not only maintaining life, but also enhancing quality of life.

Statement of the Problem

The concept, quality of life, has a number of different connotations. The terms "rehabilitation", "adjustment", and "adaptation" have been used as synonyms for quality of life. Definitions of quality of life are diverse. Difficulties exist in measuring that which the concept denotes. State of health, self-esteem, hope, family interaction, social relations, and work situation have all been used as measures reflecting quality of life (George & Bearon, 1980). As yet, no researcher in the health care field has comprehensively defined, measured, or studied quality of life.

Philosophy provides a way to consider quality of life issues. Mortimer Adler, a contemporary Aristotelian-Thomistic philosopher, points out that the primary and controlling question of human life is: "What ought a man to do in order to make his life really good?" (1971, p. 19). In his writings (1941, 1971, 1978, 1981, 1984, 1985), Adler describes the Aristotelian-Thomistic philosophical theory of the good life. Seven types of real goods (constitutive means) comprise the good life: goods of the body, goods of the mind, goods of character, goods of personal association, social goods, economic goods, and political goods. Acquisition of the first three types of goods is largely within the control of the individual; acquisition of the latter four types of goods is dependent on societal influences on the circumstances of the individual's life. In order to attain a life that is really good, it is necessary that all the goods be acquired and enjoyed in the right order and proportion. The instrumental means used to attain each good are also of significance. By possessing goods of every kind, a totality of these goods is attained. This totality is greater than the sum of its parts. "Happiness is the quality of a whole life, not of its parts" (Adler, 1941, p. 62). The moral virtues which are good habits of desiring, and good luck, are requisite to becoming happy. This Aristotelian-Thomistic philosophical theory of the good life provides guidance for a comprehensive study of quality of life. Thus, in this research, the problem of a lack of a comprehensive study of experienced quality of life was approached by studying the experienced quality of life of home hemodialysis patients in light of the Aristotelian-Thomistic philosophical theory of the good life.

Purpose of the Study

The purpose of the study was to describe the reported current quality of life of selected home hemodialysis patients in light of the Aristotelian-Thomistic philosophical theory of the good life.

Research Questions

1. What types of real goods (constitutive means) do selected home hemodialysis patients possess?
2. Of what types of real goods are the patients privated?
3. What instrumental means are involved in the acquisition of each type of real good.
4. Of what instrumental means are the patients privated?
5. What is the importance placed by the patients on each type of real good?
6. What is the proportion of time spent by the patients in attaining and enjoying each type of real good?

Definition of Terms

The definitions that follow (numbers 1 to 11) were derived from the works of Mortimer Adler (1941, 1971, 1978, 1981, 1984, 1985).

1. Quality of life is a good life or happiness in the ethical sense. It is the possession and enjoyment of all the real goods in the right order and proportion. The possession and enjoyment of the means to a good life is the measure of quality of life at any one time.
2. Real goods or constitutive means are those goods that meet the natural needs of human beings and are necessary for the attainment of a good life.
3. Apparent goods are those goods that meet wants rather than needs and are not necessary for a good life.
4. Instrumental means are the actions performed by human beings to obtain the real goods, or the set of circumstances which operate to bring about possession of the real goods.
5. Goods of the body are those perfections that relate to a person's bodily condition and functioning, such as health, vitality, vigor, and the pleasures of sense.
6. Goods of the mind are those perfections that involve a person's intellect, such as knowledge, understanding, mental abilities, spirituality, and pleasurable feelings.
7. Goods of character are a person's moral perfections, such as those of temperance, fortitude, and justice.
8. Goods of personal association are possessions in the form of a person's relationships with people, such as friends, family members, and spouses.
9. Political goods are those possessions that relate to government and governance of a person, such as political liberty, freedom of action, and protection from harm.

10. Economic goods are those possessions or financial resources that a person needs for a good life, such as free time, wealth, a means of subsistence, working and living conditions conducive to health, opportunities for self improvement, availability of health services, and opportunities for experiencing pleasures of sense.
11. Social goods are those possessions that relate to human dignity, such as equality of opportunity, equality of treatment, and equality of status.
12. Home hemodialysis is an extracorporeal treatment of renal failure in which blood is passed through an artificial kidney in order to rid the body of nitrogeneous wastes and excess fluid. This treatment is conducted in the home with the assistance of a family member or paid helper.

Significance of the Study for Nursing

There is some agreement that efforts should be made not only to prolong people's lives but to improve the quality of their lives. The requirements for attaining a good life or quality of life are clearly and comprehensively outlined in the Aristotelian-Thomistic philosophical theory of the good life; it was therefore selected for the theoretical framework of the study. One of the requirements for a good life is health. Nurses in a dialysis setting are in an excellent position to help patients with renal failure enhance the quality of their lives through the improvement of their health. It is hoped that this study of some home hemodialysis patients' current possession or privation of the types of real goods comprising a good life and the means involved in acquiring the goods will suggest future areas for study that will ultimately lead to a better understanding of what nursing care may be necessary to improve the health and, thus, the quality of life of patients with renal failure on home dialysis.

Summary

Patients with end stage renal disease on home hemodialysis undergo numerous disruptions to their lives, and it is important to determine the impact of the illness and treatment on their quality of life. However, for various reasons, conceptual and methodological, there is a lack of a suitable measure of quality of life. In this study, research questions regarding the reported current quality of life of selected home hemodialysis patients were formulated, in light of the Aristotelian-Thomistic philosophical theory of the good life. This approach was selected because it allows for a comprehensive conceptualization of quality of life.

II. LITERATURE REVIEW

The literature reviewed for this study focused on the psychosocial aspects of treatment for renal failure, and quality of life. Literature related to the psychosocial aspects of treatment for renal failure, namely the psychosocial stressors, psychosocial adaptation, coping, and depression is discussed first. Literature related to the latter topic, quality of life, is then reviewed under the following headings: conceptualization of quality of life, measurement of quality of life, and quality of life of patients with renal failure. The Aristotelian-Thomistic philosophical theory of the good life, the basis of the theoretical framework of the study, is also reviewed.

Psychosocial Aspects of Treatment for Renal Failure

Psychosocial Stressors

The technology of renal failure treatment has improved considerably over the last 15 to 20 years. Despite the technological innovations, treatment by dialysis and transplantation is considered to be highly stressful (Czackes & Kaplan De-Nour, 1978; Levy, 1974; Levy, 1977).

Numerous studies have been carried out to identify the stressful aspects of dialysis treatment (Anger, 1975; Baldree, Murphy, & Powers, 1982; Dickerson, 1980; Harris, Hyman, & Wood, 1978; Hastings, 1978; Kravette, 1978). Through the use of a scale, Baldree, Murphy, and Powers (1982) found that the major psychological stressors experienced by the 35 renal failure patients of their study were limitation of fluid intake, uncertainty concerning the future, interference with work, limitation of physical activities, and changes in bodily appearance. In this study, the patients also identified 13 additional stressors not included in the scale: attitude of hospital staff, new hospital staff members, preparation for transplantation, voice changes, increased noise level in the dialysis unit, and passing out in public with the possibility of its misinterpretation. The problems causing the least stress included reversal of family roles with children, and decreased ability to procreate. Contrary to the findings of some researchers (Anger, 1975; Dickerson, 1980), fear of death was found by Kravette (1978) to be of minor concern. Loss of self-esteem, feelings of worthlessness, and loss of sexuality have also been identified as causes of severe psychological problems in patients undergoing dialysis treatment (Hastings, 1978).

The renal failure patients' perceptions of the intrusiveness of the dialysis treatment and control over it have been thought to be related to the emotional impact of the disease. In one study of 70 dialysis and transplant patients (Devins, Binik, Hutchinson, et al., 1983-84), the patients' perceptions of the intrusiveness of the dialysis treatment and limited control over 11 life dimensions were found to correlate significantly with increased negative and decreased positive mood. In another similar study, perceived control over non-treatment life dimensions was found to be negatively related to depression (Devins, Binik, Hollomby, et al., 1981). It is of interest to note that dialysis and post-transplant patients reported having a similar amount of control over non-treatment life dimensions, and that control over the treatment dimensions was found not to be related to control over life in general.

Sexual problems seem to be common among both men and women suffering from end stage renal disease. In a non-representative survey of 1166 patients, a significant deterioration in sexual functioning, as measured by frequency of sexual intercourse, was demonstrated in both men and women (Levy, 1983). From the study, it was estimated that over 70% of male hemodialysis patients have some difficulty with impotence. Procci (1983) found, in a controlled study of 120 male subjects, that patients with renal disease had substantial deficits in erectile capacity, as measured by nocturnal penile tumescence; this was not observed in the normal control and chronic illness groups of subjects. Procci found no relationship between depression and sexual performance.

Psychosocial Adaptation, Coping, and Depression

Psychosocial adaptation, in relation to chronic illness, has been defined as a "coming to terms with the reality of chronic illness as a state of being, discarding both false hopes and destructive hopelessness, and restructuring the environment in which one must now function ... so that there is meaning and purpose in living that transcends the limitation imposed by illness" (Feldman, 1974, p. 290). Levy (1974, 1977) describes three stages of adaptation of patients receiving dialysis treatment. The "honeymoon" stage begins with the commencement of the dialysis treatment and lasts approximately six weeks to six months. This stage is marked by an emergence of hope, confidence, and lack of perception of accompanying hardships. The stage of "disenchantment and discouragement" occurs abruptly after the "honeymoon" stage. The difficulties of returning to an active productive life are realized and patients become helpless, dependent, and frustrated with their treatments. In the final stage of adjustment called "long-term adaptation", the patients begin to accept their shortcomings and learn to work within the limitations of their illnesses.

With chronic renal failure patients, the presence of family and social support has been associated with adaptation. Perceived closeness of the family has been shown to correlate with low anxiety and high self-esteem among renal transplant recipients (Simmons, Klein, & Simmons, 1977). MacElveen (1972) found that social support was associated with high morale, adherence to the regimen, and activity of dialysis patients. Dimond (1979), in her study of adaptation, used two measures of adaptation, the Behavior Morale Scale developed by MacElveen (1972) and the

Sickness Impact profile, as well as three measures of support. She demonstrated, in a sample of 36 home and incenter hemodialysis patients, that family support was associated with higher morale and fewer changes in social functioning. O'Brien (1980), using a structured interview schedule with 63 hemodialysis patients, observed that perceived support of both family members and care givers strongly correlated with compliance to the diet, medication, and treatment regimen. In another study (Harris, Hyman, & Woog, 1982), the following factors: marital status, presence of children, ethnicity, amount and kind of support, compliance, locus of control, depression, and desire to live were found to be related to adaptation. The opportunity to verbalize about the dialysis experience was also found to be an important factor in adaptation to dialysis (Kaplan De-Nour & Czackes, 1976).

In one study of adaptation to chronic hemodialysis (Kaplan De-Nour, 1981), 100 subjects were interviewed, and tested using the following psychological tests: the Wechsler-Bellevue Intelligence Test, the Shanan's Sentence Completion Techniques, the Rorschach, and the Rosenweig Tests. They were studied for two years. Significant positive correlations were found between compliance to the diet and vocational rehabilitation, between vocational and social rehabilitation, and between vocational rehabilitation and sexual potency in male patients. It was also found that vocational rehabilitation could be predicted by intelligence, lack of projection and denial, investment of energy into interpersonal relationships, and use of active coping methods. Furthermore, psychiatric complications, such as depression, suicidal risk, anxiety, and psychoses were successfully predicted. While this study produced striking results, it is impossible to judge the generalizability of the results since information about certain aspects of the methodology of the study and the reliability and validity of the instruments used was not provided in the report of the study.

Coping has been described as a process that results in adaptation. The coping patterns of 35 hemodialysis patients were studied by Baldree et al. (1982), using a reliable and content-valid scale. They found that the patients used "problem-oriented coping methods" significantly more than "affective-oriented coping methods". The two most common coping methods used by the patients included "being optimistic" and "controlling the situation", whereas the least used coping mechanisms included "putting the problem out of one's mind" and "blaming someone else". These results were also obtained by Murphy (1982). In another smaller study of 23 patients with renal failure, the relationship between psychological variables and coping was studied (Hagberg & Malmquist, 1974). The rehabilitated patient, who was thought [illegible] "be coping", in contrast to the non-rehabilitated patient, who was thought not to be "coping", was found to be more stable, to have more regular social contacts, and to hold an expectation of a fast rehabilitation. Again, since the study's methodology and instruments were not described in depth, it is impossible to determine whether the study results are generalizable.

In another study, the coping styles of dialysis patients were related to patient mortality. Harris, Hyman, and Woog (1982), in a descriptive study of 22 incenter hemodialysis patients, using a structured interview schedule, found that the patients who were classified by them as "coping poorly" survived longer than those who were classified by them as "coping adequately". This finding raises the question of the validity of the researchers' classification of the patients in terms of their degree of coping.

Depression has not only been studied in terms of a variable affecting adaptation but also in terms of an outcome indicating a problem with adaptation. Depression is considered to be common in patients with a chronic illness. The prevalence of moderate to severe depression in patients with chronic renal failure has been reported to be between 10 to 40% (Holcomb & MacDonald, 1973; Kaplan De-Nour, Shaltiel, & Czackes, 1968; Lowry & Atcherson, 1979). In one study in which self-reports were used as a measure of depression (Bonney, Finkelstein, Lytton, Schiff, & Steele, 1978), 25% of the dialysis patients who were studied reported being depressed. Similarly, Rodin et al. (1984) found that more than a quarter of the 85 dialysis patients in their study reported moderate symptoms of depression as measured by the Beck Depression Inventory, a self-report measure of the somatic and affective symptoms of depression. This instrument has been found to correlate highly with the clinical diagnosis of depression. Also, in this study, the depressed group of patients could not be distinguished from the non-depressed group on the basis of marital status, sex, educational or professional status, treatment modality, duration of treatment, or social support. It was also observed that the patients in the depressed group tended to be unemployed due to their illness.

Some researchers (Burke, 1979; Glassman & Siegel, 1970; Murphy, 1982; Treischmann & Sand, 1971) have not found an increased incidence of depression among dialysis patients. It has been hypothesized that the finding of a low incidence of depression among such patients might be a result of confounding variables such as denial. However, this hypothesis was not supported in a study conducted by Devins, Binik, Mandin, et al. (1984). Only 3 of the 70 patients in their sample receiving dialysis treatment for renal failure reported that they were depressed. However, the use of defensive denial by the patients was not observed. The authors suggested that many findings of elevated levels of depression in patients with end stage renal disease are a result of misidentification of uremic symptoms as depressive symptoms.

Quality of Life

Conceptualization of Quality of Life

Quality of life, as a concept, has recently received a great deal of attention in the literature. Numerous indices and indicators have been developed that attempt to measure that which the concept denotes. However, no definition that is consistently used exists; definitions range from descriptions of standards of living and environmental quality to life satisfaction.

Hallgren, Paterson, and Arcand (1983) define quality of life as the "way in which individuals perceive and evaluate their own lives in terms of their purposes and the circumstances in which they find themselves at a certain point in time or life" (p. 5). Atkinson (1979) describes quality of life as a multidimensional concept, of which life satisfaction is one dimension. He suggests that there are numerous other dimensions of which we may not yet be aware. Shaw (1977) mathematically conceptualizes quality of life as $QL=NE \times (H+S)$, where QL represents quality of life, NE represents the patient's natural endowment (physical and intellectual), H represents contributions made to the individual by his home and family, and S represents contributions made on his behalf by society. It is therefore conceivable, although hardly possible, that an individual may have no (that is zero) quality of life if he has no actual endowment or is deprived in his environment. George and Bearon (1980) define quality of life in terms of four underlying dimensions: life satisfaction, self-esteem, general health and functional status, and socioeconomic status (p. 6). The authors suggest indices that measure each of these dimensions. Yet other authors proceed with the development of instruments without descriptive or operational definitions of quality of life (Alexander & Willems, 1981; Daughton, Fix, Kass, Bell, & Patel 1982; Spitzer et al., 1981; Tucker, Milkerne, & Ziller, 1982). It has been suggested that quality of life is a concept that cannot be measured; once it is defined, specific dimensions of it which are delineated can be numerically measured (Bedau, 1982, p. 113).

The conceptualization of quality of life has been problematic, particularly in light of the controversy about the nature, meaning, and definition of the concept, quality of life. Diener (1984) pointed out that some progress has been made in the last decade but that a closer connection must be made between theory and research relating to quality of life. Various theories have been used to explain quality of life and measurement of it varies according to the theory used.

Perhaps the best known study of quality of life is the one that was conducted by Campbell, Converse, and Rodgers in 1976. After reviewing the quality of life literature, Campbell et al. found it necessary to choose between Bradburn's (1969) conceptualization of quality of life as "happiness" and the "satisfaction" approach of Cantril (1965). The satisfaction of needs approach was selected and satisfaction with regard to several domains of life were studied: marriage, family life, health, neighbourhood, friendships, housework, job, life in the United States, city or country, non work, usefulness of education, standard of living, amount of education, and savings. Satisfaction with a domain of life was seen as dependent on the individual's assessment of various attributes of that domain.

Andrews and Withey (1976) conceptualized quality of life as well being. They conceived two levels of indicators of well-being: global indicators reflecting overall well-being, and specific domain indicators and criteria indicators reflecting well-being in the domains of life. They envisioned a two-dimensional conceptual model with domains of life (e.g., job, family life) on one axis and criteria pertaining to the domains of life (e.g., success, beauty, fun) on the other axis. Global measures were thought to be the combination of domain and criteria measures. However, in 1983, McKennell and Andrews demonstrated that the domain measures had no direct impact on some global measures or "life-as-a-whole assessments" (p. 98). Instead, the contribution of the domain measures was found to be indirect; the subjects' perceptions of the domains of their lives affected the global assessments of their lives.

Liu (1974) considered quality of life to be a concept that varies across time, place, and individuals. He defined it as the output of two input factors: physical factors, such as quantifiable goods, services, and material wealth; and spiritual factors, such as esteem, self-actualization, community belongingness, and other psychological factors. Much of the recent work on social indicators of quality of life has been based on Liu's conceptualization of quality of life.

From a review of the philosophical and theoretical literature, Shin and Johnson (1978) developed a model for the study of quality of life in which happiness consisted of the individual's perceptions of his/her unique needs and resources in relation to aspects of his/her environment or culture. The model was tested empirically with satisfactory results. A multiple correlation score of .60 was obtained when 20 predictors were correlated with the dependent variable, happiness.

Cardus, Fuhrer, and Thrall (1981) derived a model for assessing quality of life from the general theory of benefit-cost analysis. Three categories of benefits were described by them: monetary benefits, direct benefits, and indirect benefits. The authors, realizing that no valid measures of non-monetary benefits exist, suggested that available hard data (number of dollars) be used along with subjective scales for the most accurate assessment of quality of life.

According to Harwood (1976), there are three types of quality of life models: ascriptive, testimonial, and importance. An ascriptive model is based on a selection of indicators by a committee of experts without consultation with the public. One of the most comprehensive ascriptive models was proposed by the

Economic Council of Canada (1971). Numerous components were listed under three specific dimensions: political, economic, and social. Health was listed as a component of the social dimension. In a testimonial model, a subjective, individual-centered model of quality of life within a measurement framework is used. The models of Andrews and Withey (1976) and Campbell et al. (1976b) fall into this category. Studies have demonstrated the use of what is called an importance model (Harwood, 1976). In this type of model, the attitudes and values of persons in relation to a set of quality of life components are ranked. In "importance" studies, the ordering of quality of life priorities has been found to be: 1) health, 2) employment and income, and 3) environment, communication, and public safety (Harwood, 1976).

In Harwood's study (1976), a testimonial and an importance model were used along with the Economic Council of Canada's ascriptive model. One hundred and fifty volunteers were used to test the models. Many commonalities were found among the models in terms of their dimensions: health, freedom, education, leisure, and family. Harwood concluded that a consideration of political and economic factors was basic to an understanding of quality of life. The social component, which included health, was found to be diffuse and difficult to formulate.

The conceptual models that have been described thus far have been used in studies of large groups of people, primarily social and cultural groups, but on the whole, these models have not been used in studies of populations in the health care areas. Also, the unit of analysis for these studies has generally been a group. It seems that it might be more appropriate to consider the individual as the unit of analysis, since, as McCall (1975) suggested, quality of life is something that applies basically to individuals, and subsequently can only be extended to groups through a summative procedure.

Many different models of quality of life have been developed and used by health care researchers. For instance, Hallgren et al. (1983) used a model comprised of life dimensions (e.g., family relationships, social activities, communications), population dimensions (e.g., age, marital status, education, socioeconomic status), and treatment dimensions (e.g., surgery, radiation, chemotherapy) in their study of quality of life of breast cancer patients.

Measurement of Quality of Life

Several approaches have been used to measure experienced quality of life. Traditionally, in the medical context, morbidity and mortality have been used as outcome measures. With the increasing interest in quality of life, these measures have been expanded to include physical functioning, psychological condition, and occupational and social rehabilitation. Objective factors, such as the possession and consumption of goods and services, are often used by economists to demonstrate quality of life. However, these indicators do not address subjective assessments of happiness and/or satisfaction as they relate to the life plan of the individual (Bedau, 1982, p. 100). Both objective and subjective measures are necessary for a comprehensive measurement of quality of life. Conceptualizations of quality of life vary widely, and innumerable measures of quality of life exist. Since many of these instruments measure things other than quality of life or only some facets of it, it is important to understand the true meaning of the concept, quality of life, so that experienced quality of life can be accurately studied.

The avowed happiness of people has been used as a measure of quality of life. However, the concept, happiness, has not been clearly defined. In some studies, it has been identified with feelings of pleasure, that is, the transient psychological state of contentment. Quality of life instruments that assess psychological happiness have been developed by Andrews and Withey (1976), Bradburn (1969), Zautra, Beier, and Cappel (1977), and Shin and Johnson (1978). Bradburn (1969) defined happiness as the extent to which positive feelings outweigh negative feelings, using the last few weeks of life as the time reference. In contrast, Aristotle identified happiness, in an ethical sense, as the chief and final good to be sought by human beings (Adler, 1985).

Life satisfaction is thought to be a distinctly different concept from that of happiness. It has been defined by George (1979) as an assessment of the overall condition of a person's life, which is made by comparing a person's aspirations to his/her achievements (p. 210). Campbell et al. (1976b) used life satisfaction as the theoretical basis of their study of the quality of American life. The quality of life instrument developed by Campbell et al. permits a global assessment of well-being as well as an assessment of satisfaction in certain domains of life. Its stability reliability score has ranged from .42 to .67 on various items, over an eight month period of time. The concurrent validity score of the aspect of the instrument measuring satisfaction in various domains of life has been found to be .72 in relation to the Global Index of Well Being. An interesting finding of this study was that of a close relationship between job satisfaction and general life satisfaction. It should be noted that, although Campbell et al. decided to use life satisfaction rather than happiness as a measure of quality of life, they included several indicators of happiness in their instrument. This inclusion seems to indicate that Campbell et al. were not consistent in their approach to the measurement of quality of life.

Another satisfaction measure, Cantril's self-anchoring scale (1965), consists of a ladder with rungs which depict the best to worst possible life. Individuals identify where they believe they are on the ladder, thereby indirectly reflecting their satisfaction with their lives. The scale was administered repeatedly to

Americans between 1959 and 1974. No changes in the subjects' rating of their life satisfaction were observed over time. Although one might expect increased satisfaction with increased standard of living, Campbell et al. (1976b) hypothesized, in relation to Cantril's finding of no change in life satisfaction, that individuals adjust their expectations in response to changes in their life situations. Their changed expectations are then reflected in their ratings of satisfaction with their lives.

Flanagan (1978) began his study of quality of life by establishing the dimensions of quality of life, using an inductive approach. He collected and classified 6500 critical incidents of positive and negative life experiences. Fifteen quality of life categories were formulated. Flanagan then interviewed a nationally representative sample of people, using a structured questionnaire based on the quality of life categories he had formulated. The sample consisted of 1000 people in each of three age categories (30 years, 50 years, and 70 years). Flanagan found that 85% of the subjects reported that their overall quality of life was good or better than good. There was a striking similarity between the responses of people in the three age groups and between the sexes.

In the health care field, numerous health status instruments have been used to measure experienced quality of life. Berg, Hallaus, and Berk (1976) used an indirect approach to develop a health status index. They had 150 health care workers rate 50 items on a scale from zero to ten in terms of their value with regard to the quality and meaningfulness of life. The results indicated that cognitive, emotional, and social functions were rated as being most important by this group. It was suggested that patients' perceptions of the importance of the items may be significantly different from those of health care workers. Ziller (1974) stated: "quality of life is in the eye of the experiencer" (p. 301); this suggests that the individual patient may assess his/her quality of life differently than his/her health care provider.

Kaplan and Bush (1982) described a cost/utility ratio that expressed the output of health care programs in terms of the number of years of well life remaining and the health-related "quality of life" offered by a specific program. Functional level scales and symptom lists were used to determine quality of well-being. High levels of convergent, divergent, and concurrent validity of these measures were demonstrated. The term, "well-year", was used to describe a year of completely well life, free of dysfunctional symptoms and health-related problems. If a disease reduced a person's quality of life by half, .5 Well-Year was subtracted. In patients undergoing hospital renal dialysis, the estimated cost/utility of the treatment was greater than $50,000 per "well-year". The authors suggested that consideration of the cost/benefit implications of this treatment would create controversy over whether hospital dialysis programs should be funded.

Sackett and Torrance (1978) took a different approach to the measurement of various health states. They presented subjects with two scenarios concerning health states. In each scenario, the duration of time a certain health state would be experienced was specified. The subjects were asked which scenario they preferred. The time periods that the subjects would remain in each health state were adjusted until the subjects no longer preferred one over another. A utility score of a health state, based on death as zero and one as perfectly healthy, was calculated. In the study, 29 home dialysis patients and 246 individuals from the general population were studied. While the approach is an interesting one, no attempts were made to establish the statistical reliability and validity of the measure. Therefore, it is impossible to know whether the instrument is appropriate for use in another study.

Numerous health care researchers have used medical, psychological, or rehabilitation frameworks to measure the experienced quality of life of various patient groups. Lewis (1982) studied the relationship between personal control and quality of life in 57 late stage cancer patients. To measure quality of life, Lewis used the Rosenberg Self-Esteem Scale, the Parsell Anxiety Scale, and the Crumbaugh Purpose-in-Life Test. A positive correlation between control over life and the "quality of life" measures was observed. Although all these scales have reasonable reliability scores (.85 - .92 for the Self-Esteem Scale; .79 - .90 for the Anxiety Scale; and .85 for the Purpose-in-Life Test), their validity scores were considerably lower. On testing, the Rosenberg Self-Esteem Scale had a concurrent validity score of .60 in relation to the Coopersmith Self-Esteem Inventory. The Self-Esteem scale was found to correlate with clinical judgement of the patients' self-esteem; the validity scores ranged from .56 to .83. When the Purpose-in-Life Test was compared with the therapist's rating of the patients' purpose in life, a correlation score of only .38 was obtained. Similarly, the validity score for the Anxiety Scale, when compared with a measure of perceived functional effectiveness, was found to be only -.27. These findings suggest that these measures may not be truly measuring what they are purported to measure, and that the study results should be interpreted with caution.

Spitzer et al. (1981) developed a QL-Index which physicians could use to measure the quality of life of cancer patients. The dimensions of activity, daily living, health, support, and outlook were included in the Index. The validity and reliability of the Index were established in studies which included 879 patients with many types of physical disease. An internal consistency reliability score of .775 and an intrarater reliability score of .81 were obtained. Forty-three individuals (patients, relatives, and health professionals) were used to test the content validity of the instrument, and over 51% agreement was attained on all items. Discriminant validity was demonstrated when high scores were attained by healthy subjects, and low scores by subjects who were seriously ill. Since the instrument was found to discriminate between these groups of people, it would perhaps be an appropriate one to use for the measurement of quality of life of a number of patient groups.

Padilla et al. (1983) also developed an instrument to measure the quality of life of cancer patients. The instrument, a self-rating scale, included 14 items concerning general physical condition, normal activities, and personal attitudes regarding general quality of life. When the instrument was tested for its [illegible]ability reliability, the correlation scores ranged from .11 to .97. Also, an internal consistency reliability score of .88 was obtained. Its concurrent validity in relation to another scale (the Karnofsky physician estimate) was found to be moderate (R^2=.29). However, in this case, it was difficult to determine which instrument was or was not measuring quality of life. The instrument under study was found to discriminate between groups of inpatients, outpatients, and non-patients. However, the variable reliability of the instrument suggests that the study results must be interpreted with caution.

Hallgren et al. (1983) developed an instrument to assess the quality of life of breast cancer patients by carrying out a factor analysis of 68 indicators of quality of life that they had identified through an analysis of data gathered through patient interviews and a Q-sort. The dimensions of quality of life resulting from the factor analysis and included in their instrument were physical well-being, sexuality and body image, extrapersonal relationships, coping, mother/wife role, personal values, outside activities, self acceptance and acceptance by others, dealing with loss, information and communication, and social activities. When the instrument was tested for its reliability, a reliability score of .867 was obtained. Its face and content validity were established with the assistance of a panel of five experts. A factor analysis demonstrated a relatively high degree of congruence (.374 to .780) among the dimensions. The results indicated that the breast cancer patients receiving adjuvant treatment experienced the greatest negative impact in terms of their quality of life.

Palmer, Walsh, McKenna, and Greening (1980) also studied the quality of life of patients receiving adjuvant chemotherapy for breast cancer. However, they primarily measured the side effects of the treatment. Since this study did not measure other aspects of the quality of life of these patients, it was an incomplete study of experienced quality of life.

Several writers advocate the use of measures of functional status as quality of life indexes (Alexander & Willems, 1981; Daughton et al., 1982; Liang, Cullen, & Larson, 1982). One well-known indicator that has been used as a measure of quality of life is the Index of Well-Being developed by Kaplan, Bush, and Berry (1976). In this Index, functional levels are assessed through scales that measure mobility, physical activity, and social activity. The instrument was tested extensively for its reliability and validity (Kaplan et al., 1976). A parallel forms reliability score of .91 was obtained. Convergent and discriminant validity were established by correlating the Index with the number of chronic illnesses experienced by the subjects. A score of -.96 was obtained. As well, the correlation between the number of physician contacts made by the subjects and well-being was found to be .55. While the measures used to validate the Index do not truly reflect quality of life, it is likely that no other suitable instruments were available for validation purposes. Unfortunately, the Index only attempts to measure one dimension of quality of life, namely functional status. It should not, therefore, be purported to be a measure of quality of life.

In arthritics, the Lee Index of Functional Capacity has been shown to be sensitive to significant improvements in functional ability (Lee & Kundraik, 1973). Chambers et al. (1982) found that the stability reliability scores ranged from .48 to .70, and the internal consistency scores ranged from .51 to .76 when the Index was tested with arthritic patients. The Lee Index is not the best available measure of quality of life, since it measures only one dimension of quality of life.

In an attempt to measure the quality of life of patients with burns, Blades, Jones, and Munster (1979) designed a scale to compare pre and postburn levels of work, dependence, joint function, psychological state, and subjective assessment of quality of life. They found that the patients achieved higher scores one year postburn than preburn. The reliability and validity of the scale were not described by the authors, making it impossible to determine the generalizability of their findings.

Studies using both objective and subjective measures of quality of life are increasing in number. Penckoffer and Holm (1984), using Cantril's self-anchoring scale (1965), level of angina, and level of physical activity to measure the quality of life of 34 coronary artery bypass patients, found significant improvements in the quality of life of these patients early in the recovery period following surgery.

In a study of 278 mentally disabled residents of 30 Los Angeles board-and-care homes, quality of life was assessed by examining eight areas of life: living situation, family relationships, social relationships, leisure activities, work, finances, personal safety, and health. Questions related to these areas were developed from items of existing quality of life instruments. On testing, the internal consistency reliability scores of the instrument ranged from .74 to .87. The authors recognized the need for further testing of the instrument for stability reliability, inter-rater reliability, and validity. They questioned "what measures truly reflect quality of life" (Lehman, Ward, & Linn, 1982, p. 1273). The study results indicated that the residents were dissatisfied with their finances, unemployment, and personal safety.

Quality of Life of Patients with Renal Failure

The experienced quality of life of patients receiving treatment for renal failure has not been satisfactorily studied. Both conceptual and methodological problems abound in existing studies. Levy and Reichsman (1975) attempted to evaluate the quality of life of 18 incenter hemodialysis patients. After several indepth interviews, the investigators rated each patient's quality of life as good, fair, or poor. In this small sample, only one third of the patients were rated as having a good quality of life. The patients' assessments of their quality of life were not considered. No attempts were made to validate the researchers' assessments, so the results must be interpreted with caution.

Jackle (1974) used Cantril's self-anchoring scale to determine the life satisfaction of 30 hemodialysis patients. In a ladder type of scale with steps ranging from zero to ten, the dialysis patients, on the average, placed themselves at 5.5, that is, midway between the best and worst possible life. The subjects of a control group, on the average, placed themselves at the 6.6 point of the scale. The most important components of life were found to be health, autonomy, and relationships with others. The reliability and validity of the scale were not discussed in the report of the study, making it difficult to assess the generalizability of the study findings.

Murphy (1982) used a multivariate psychological approach to examine the adjustment and quality of life of 150 chronic hemodialysis patients from nine dialysis units. A series of instruments designed to measure level of stress, coping mechanisms, social functioning, depression, and adjustment were administered to the patients. Murphy's results were similar to those of other researchers: the patients reported that fluid restriction was the most severe stressor, a problem-oriented way of coping was the coping mechanism most used by the patients, depression was minimally evident, and the patients were non-compliant in relation to fluid restrictions. While the study was methodologically sound, it could be queried whether the psychological measures which were used were indeed measuring quality of life. It would appear that only selected aspects of the concept were measured and that a comprehensive assessment of quality of life was not carried out.

Johnson, McCauley, and Copely (1982) attempted to evaluate comprehensively the quality of life of hemodialysis and transplant patients. Without the benefit of a conceptual framework, the researchers developed an instrument by combining sub-scales from the works of Campbell et al. (1976b), Bradburn (1969), and Holmes and Rahe (1967). Fifty-nine dialysis and transplant patients were studied. It was found that the renal transplant recipients, in comparison to other Americans, had a normal quality of life. While the hemodialysis patients awaiting their first renal transplant had a near normal quality of life, the hemodialysis patients in whom renal transplants had failed had a substantially lower quality of life. Since the reliability and validity of the developed instrument were not described by the researchers, it is impossible to assess the generalizability of the study results. Also, these results have been refuted by Binik, Devins et al. (1984) because of the theoretical and methodological issues that threaten the validity of the conclusions.

Findings contrary to those of the Johnson et al. study (1982) were found by Binik, Devins et al. (1984), in two studies with sample sizes of 80 and 70 respectively. Using a large number of measures, namely the McGill Pain Questionnaire, the Beck Depression Inventory, the Self-Esteem Inventory, the Internal-External Locus of Control Scale, the Health Locus of Control Scale, the Hamilton Psychiatric Rating Scale for Depression, the Profile of Mood States, the Affect Balance Scale, the Life Happiness Rating, and other self-ratings of distress, perceived control, and intrusiveness, Binik, Devins et al. found no significant differences among dialysis patients, dialysis patients with a history of previous transplant failure, and patients with functioning renal transplants.

Kaplan De-Nour and Shanan (1980) also compared the quality of life of 20 dialysis patients and 11 patients with functioning renal transplants. Using clinical assessments as well as psychological tests (Rorschach test, Shanan Sentence Completion Technique, and a questionnaire designed to yield measures of coping behaviour) as measures, the researchers found that two thirds of the renal transplant patients were free of psychiatric symptoms as compared to only one third of the dialysis patients. No differences were found between the two groups in the area of social activities, and there was only slightly better vocational rehabilitation among the transplant recipients. Kaplan De-Nour and Shanan (1980) suggested that the corticosteroids taken by the renal transplant patients may have been responsible for their greater sense of well-being.

The terms, rehabilitation status, adjustment, and quality of life have been considered as synonymous by some authors. Kutner and Cardenas (1981) used semi-structured interviews, a self-rated satisfaction scale, the Zung depression scale, and 11 tests of cognitive-motor skills to determine the medical, vocational, and psychological rehabilitation of 137 dialysis patients. The patients between the ages of 25 and 34 years were found to have the best overall adjustment. Depression was a problem in patients over 55 and under 25 years of age. In another study of 62 renal transplant recipients, 83.8% of the subjects who participated were considered to be socially and occupationally rehabilitated. However, since the reliability and validity of the survey instrument were not addressed by the researchers, and biased sampling as a result of self-selection might have been a problem in this study, it would be inadvisable to attempt to generalize the findings.

In a more comprehensive study of renal transplant recipients, Simmons and Kamstra (1980) studied the physical, social, and emotional well-being of 237 renal transplant recipients at four points in time, from pretransplantation to five to nine years posttransplantation. A survey instrument that included well known scales for measuring self-esteem and depression was used. The reliability and validity of this instrument were reported to be satisfactory, although the test scores were not reported. The following findings should therefore be interpreted with caution. The nondiabetic, long-term transplant patients showed high levels of improvement and rehabilitation on multiple dimensions over time. The diabetic transplant patients also demonstrated improvement but generally had more problems than the non-diabetic transplant patients. As well, the patients with fewer economic and family resources and the patients with Cushingnoid features were less well adjusted than the patients without these added problems.

In another study by Kaplan De-Nour (1982), one dimension of quality of life, "social adjustment", was assessed in 102 chronic hemodialysis patients. A questionnaire on leisure activities, that had not been tested for its reliability and validity, was administered. The results indicated that the patients' interest in individual, family, and social activities decreased over time. Nearly 50% of the patients reported that they rarely participated in social leisure activities. It was suggested that these patients might have a better quality of life, if hospital staff helped them to increase their social participation. However, this suggestion is somewhat premature given the preliminary nature of this study and its use of an instrument with unproven reliability and validity.

A modified "time trade-off" technique was used to estimate the perceptions of 42 hemodialysis patients, 17 peritoneal dialysis patients, and 14 transplant patients, with regard to the utility or worth of their health state (Churchill, Morgan, & Torrance, 1984). The patients were presented with two hypothetical options: continuing in their present health state for a lifetime or accepting a shorter time in a state of full health. The shorter time was then adjusted until a point of equivalence was reached. This point was where the patient could no longer choose between the options. This point was taken to be the utility state. It ranged from 0 for death to 1.0 for perfect health. When this technique was tested for its reliability and validity, a test-retest score of .628 was obtained. A rank correlation score of .51 between utility state and nephrologists' assessment of the patients' quality of life demonstrated the concurrent validity of the measure. In the study, the following mean utility state scores were obtained: .57 for hemodialysis patients, .57 for continuous ambulatory peritoneal dialysis patients, and .80 for renal transplant patients. This measure has significant limitations. It gives a global, although hardly comprehensive, picture of quality of life. Also, factors other than treatment modality need to be addressed in an assessment of quality of life. Furthermore, the relatively low reliability and validity scores of the measure suggest that the findings should be interpreted with caution.

Campbell (1981), a patient with renal failure, developed a conceptual model of quality of life based upon four constructs: general life satisfaction, self-esteem, family cohesion, and social isolation. He designed and used a self report questionnaire comprised of four scales, one for each construct, in a study of 105 patients receiving a variety of treatment modalities for renal failure. Campbell found that greater independence with regard to the treatment regimen, higher socioeconomic status, and higher levels of social integration were associated with a higher perceived quality of life.

Bonney, Finkelstein, Lytton, Schiff, and Steele (1978) studied survival and quality of life of patients receiving treatment for renal failure. They used an interview approach, the National Kidney Foundation functional classifications, and the Kupfer, Detre System for assessing psychological status. Again, the reliability and validity of the measures were not discussed in the report of the study so it is impossible to assess the accuracy and generalizability of the results. The data suggested that hemodialysis patients have a significantly impaired quality of life. The patients tended to be unemployed, inactive physically, and moderately depressed. As well, they had symptoms of organic brain dysfunction, numerous physical complaints, and decreased frequency of sexual intercourse. While the renal transplant patients had overall higher levels of functioning, their post-dialysis levels of functioning were lower than their predialysis levels of functioning.

Rozenbaum, Chaimovitz, and Bearman (1984) measured employment, sexual activity, and physical activity in their study of the quality of life of 106 chronic dialysis patients. They found that only 47% of the patients worked, only 47% of the married patients were sexually active, and only 22% of the patients could engage in normal physical activity. The patients under 60 years of age and those with more than 13 years of education achieved higher scores than younger and less well educated patients. No attempts were made to validate the instrument in this study, so, again, the accuracy and generalizability of the findings cannot be assessed.

Laborde and Powers (1980) compared the life satisfaction of 20 patients undergoing hemodialysis and 20 patients suffering from osteoarthritis. Cantril's self-anchoring scale was used to examine the patients' satisfaction with their past, present, and future lives. While both groups were equally satisfied with their past lives and no significant difference was found with regard to their satisfaction in terms of their future lives, it was interesting to note that the patients receiving treatment with hemodialysis rated their satisfaction with their present lives higher than did the patients with arthritis. The researchers suggested that lack of pain in the hemodialysis patients may have been a significant factor contributing to this difference.

In one recent study (Evans et al., 1985), the quality of life of 859 patients undergoing dialysis or transplantation was assessed. Subjective measures of life satisfaction, well-being, and psychological affect (used by Campbell et al. 1976(b) in their study of quality of life) were used. Objective measures used included the Karnofsky Index, as an indicator of functional impairment, and the self-reported ability to work (which is not truly an objective measure). On testing for the validity of the instruments, the correlation scores between pairs of the three subjective measures ranged from .60 to .93 and the correlation scores between the two objective measures was .42. These findings suggest that these measures do not reflect one concept. The reliability of the data was not discussed by the researchers in their study report. In the study, it was found that the patients with renal transplants had the highest quality of life, followed by patients on home hemodialysis. This difference persisted even when demographic variables (age, sex, race, education, and presence of other illnesses) were controlled statistically. Although the quality of life of the transplant recipients compared favourably with that of a general American population, the patients on dialysis were found not to be working or functioning at the same level as people in the general population.

In summary, the difficulties in measuring experienced quality of life have largely arisen from the lack of a satisfactory theoretical base. The development of a systematic research base is therefore precluded. Unfortunately, often, no distinction has been made among concepts such as happiness, life satisfaction, or morale. Some researchers have used global measures of quality of life, while others have focused on specific domains of quality of life. Problems relating to the sensitivity of the instruments to change in condition, age, and other variables still exist. In some studies, the unit of analysis was the individual while in others it was the society. As well, there is a distinct possibility that some specific domains of life conceptualized by some researchers as reflective of quality of life are pertinent to only one major cultural group (Kennedy, Northcott, & Kinzel, 1978). The domains of life that are necessary or important for all human beings need to be identified and studied. Despite the great gains that have been made in the area of social science methodology, there is still no consensus as to what quality of life is and how one measures it (Horowitz, 1979). The opinion of many authors is that there is no generally acceptable valid measure of quality of life (Berg et al., 1976; Gehrmann, 1978; Hallgren et al., 1983; Moore, 1978; Spitzer et al., 1981). It has been asked whether the research findings related to quality of life are worthwhile for only academic rather than practical purposes (Gehrmann, 1978).

Theoretical Framework

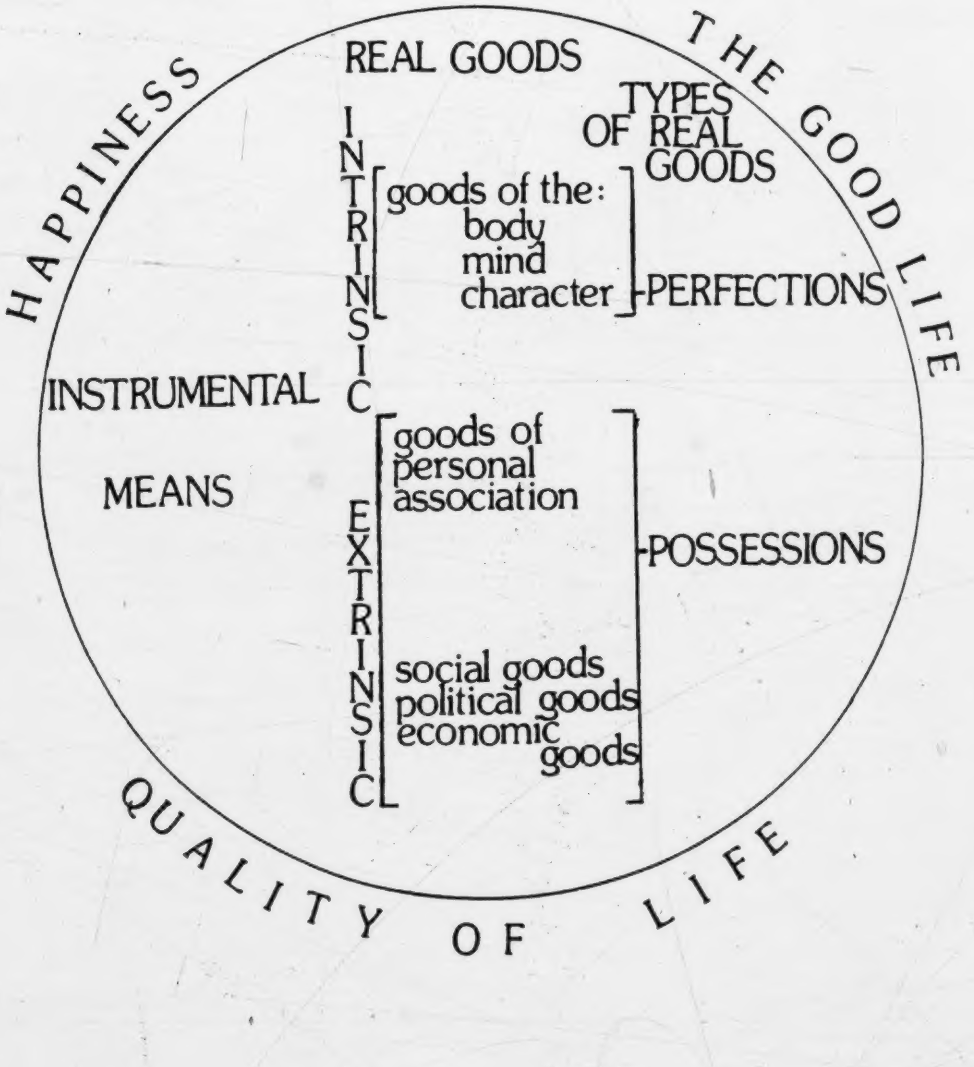
The Good Life

The concept, quality of life, has been examined from a number of perspectives. A number of scientists, ethicists, and others have proposed criteria for the "good life" or "ideal life". For the purpose of this study, quality of life is defined as the good life or happiness in the ethical sense. The theoretical framework of this study is based on the Aristotelian-Thomistic philosophical theory of the good life. It consists of propositions about the real goods that must be attained and enjoyed in the right order and proportion for a person to have a good life and the instrumental means to such goods. These propositions are those that have been proposed by Adler (1941, 1965, 1971, 1980, 1981, 1984, 1985), a contemporary Aristotelian-Thomistic philosopher. Figure 1 depicts the theoretical framework.

Adler (1971) outlines seven types of real goods (goods of the body, goods of the mind, goods of character, goods of personal association, social goods,

FIGURE I

THEORETICAL FRAMEWORK – THE GOOD LIFE


HAPPINESS
THE GOOD LIFE
QUALITY OF LIFE
REAL GOODS
TYPES OF REAL GOODS
INTRINSIC
goods of the:
body
mind
character
PERFECTIONS
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MEANS
EXTRINSIC
goods of personal association
social goods
political goods
economic goods
POSSESSIONS

economic goods, and political goods) that are necessary for any individual to attain a good life. The good life is equated with happiness in the ethical sense. Adler contrasts this type of happiness with the transient psychological state of happiness which perhaps would be better termed as "contentment" (1985, p. 132). Enjoyment of the real goods (in the ethical sense) refers to the experiencing of the goods. Happiness or the good life cannot be achieved at any one moment in a person's life. "Only when it is all over can we say that it was a good life, that the individual who lived it achieved happiness" (Adler, 1984, p.91). In essence, "'happiness' stands for a whole human life well lived, a life enriched by all real goods – all the possessions a human being should have, all the perfections that a human being should have, all the perfections a human being should attain" (Adler, 1984, p.90).

Adler (1984) modified the following statement made by St. Augustine, "Happy is the man who, in the course of a complete life, attains everything he desires provided he desires nothing amiss" by adding the thought, "also provided that he has the good fortune that bestows upon him other goods which are not entirely within the power of his own free choice" (p.92). In relation to his modification, Adler cited Aristotle's statement, "Happiness consists in a complete life, lived in accordance with virtue, and accompanied by a moderate possession of external goods" (p.115). In other words, good habits, such as the moral virtues, which are good habits of desiring, are necessary but not sufficient for attaining each of the real goods, and the totality of goods or happiness. Crucial to the attainment of a good life over time are the moral virtues and good luck.

Happiness itself is the ultimate end to be sought by all human beings. It consists of the sum of all the real goods and is not the highest good. It is the ultimate good because it leaves nothing more to be desired. All people have an obligation to seek and pursue a good life because it it a life befitting human beings. Also, by virtue of this obligation, all people have a natural right to seek and pursue a good life (Adler, 1981).

The real goods are the constituents of a good life and are the constitutive means to a good life. They are really good because they meet the natural needs of all human beings. Some real goods, such as money, an economic good, serve only as means to the attainment of other real goods and are not desired for their own sake. Other real goods, such as knowledge, serve as means to other real goods and are desired for their own sake. Yet other real goods, such as wisdom, are desired only for their own sake, and not as means to other real goods. However, they are constitutive means to the ultimate good, a good life (Adler, 1981).

It is important that the real goods be sought and enjoyed in the right order and proportion for the attainment of a good life. The order of real goods refers to whether the good serves as an end in itself, or only as a means to another real good (i.e. as a mere means). Proportion, in relation to the real goods, refers to the amount of time spent in the attainment and enjoyment of a real good, particularly as it relates to the attainment and enjoyment of another type of real good (Adler, 1981). Adler (1985) stated that all of the real goods are not equally good. The goods of lower order are things that are good only in moderation, such as money. Such goods serve as mere means and ought not to be desired for their own sake. The spending of too much time in the attainment and enjoyment of these goods could interfere with the acquisition and enjoyment of other real goods; therefore, the time spent in the attainment and enjoyment of such goods should be limited. The goods of higher order (e.g., goods of the mind, goods of character) are unlimited in the sense that we cannot obtain too much of them. They are those things that perfect a person. They speak to our humanness. Right order and proportion involves spending as much time as possible in attaining and enjoying the goods of higher order, provided that this does not interfere with the attainment of the other real goods.

In contrast to the real goods, apparent goods, which answer to wants or desires that individuals acquire, are not necessary for a good life (Adler 1981, p. 219) since they do not meet natural needs. Apparent goods are either noxious or innocuous, depending on whether or not they interfere with the attainment and enjoyment of any of the real goods (Adler, 1984). They should be sought only if the seeking of them does not interfere with the acquisition and enjoyment of the things that are really good for us, that is, the real goods (Adler, 1981).

The real goods can be thought of in terms of possessions and perfections. Possessions are goods that exist apart from the person; they include the goods of personal association, and the political, social, and economic goods. In contrast, perfections are internal goods which perfect a person. They exist in a person rather than apart from him/her. They include the goods of the body, mind, and character (Adler, 1981, p. 86).

The real goods can also be thought of in terms of extrinsic and intrinsic goods. The intrinsic goods exist within a person and possession of them is largely under the control of the individual. The intrinsic goods include the goods of the body, mind, and character. The extrinsic goods are goods that exist apart from the person and possession of them never solely depends on what the individual chooses to do; possession of them depends on circumstances beyond an individual's control. Extrinsic goods include the goods of personal association and the social, political, and economic goods (Adler, 1981, p. 87).

Possession of the extrinsic goods is dependent upon the society in which we live. For example, in some societies, freedom and equality are guaranteed, while in other societies, these goods are not available to the common man. "A good society, a society in which the common good of the people is served and advanced, contributes to the good life of its individuals" (Adler, 1978, p. 107). Similarly, "The most just form of government is a republic with universal suffrage and with a constitution that includes a bill of economic as well as political rights that secures the natural rights of all" (Adler, 1981, p. 195). If a person is to attain all the real goods, he/she must not only lead a good life but must also live in a good society (Adler, 1978).

The instrumental means are the actions that are undertaken by the individual and the circumstances that operate in the attainment of the real goods (Adler, 1981). Under certain circumstances, a number of instrumental means could be involved in the acquisition of a real good. Also, different people may use different means to attain the same real good. Some instrumental means may be operative in terms of attaining the proximate end, that is, an immediately required real good, but may interfere with the attainment of the ultimate end, that is, the good life. For instance, working in a plant, in which hazardous chemicals are manufactured, could serve as an instrumental means to the real good, wealth, but, in the long run, such a means could interfere with the attainment of a good life by privating the individual of other real goods or constitutive means to the good life, such as health. It follows, then, that, in such cases, attempts should be made to look for a better means to wealth.

The Real Goods

Goods of the Body

Goods of the body include those real goods that are related to the body, such as health, vitality, vigor, and pleasures of sense. These goods are necessary in order to live. "...Without life we cannot live well" (Adler, 1981, p.151). Health may be a means to other goods such as educational pursuits that in turn contribute to the attainment of goods of the mind. Sufficient quantities and types of sleep, food, and drink are necessary to attain goods of the body. While many things can be done by a person to manage his/her life so that the goods of the body can be attained, the attainment of these goods may also be affected by factors outside a person's control, such as the political environment and access to medical care.

Goods of the Mind

Goods of the mind include all the intellectual goods, such as knowledge, a modicum of wisdom, understanding, creativity, and prudence (Adler, 1984, p.98). Prudence is a good habit formed by "repeated acts of deliberating well in order to reach sound judgements or decisions" (Adler, 1984, p. 98). Mental abilities, such as the ability to remember, are also goods of the mind. Although Adler does not discuss to what type of real good feelings of a positive nature, such as contentment, and beliefs about a higher being (or faith) belong, pleasurable feelings and spirituality have been placed into this category of goods since they involve the mind or intellect. They arise from our memories, imagination, hopes, knowledge, and understanding; they are more than natural instincts. Strictly speaking, the term, "feelings", as used in this study, refers to what Thomistic philosophers seem to call "sentiments" (Gilson, 1956). However, the term, "feelings", is used in this study since it is a term that is more familiar to most people.

Adler (1984) sees goods of the mind as among the highest in the scale of real goods since they serve to perfect the individual and they are essential components of humanness. The goods of the mind can serve as ends in themselves or as means to other real goods. As well, they always serve as means to the good life. Leisure activities are one set of instrumental means that assist in the attainment of intellectual goods. Adler defines leisure as "any mode of useful and productive activity that is not biologically or economically necessary and that, since it always involves learning, is self-creative or self-improving" (1970, p. 36).

Goods of Character

Goods of character, that is, the moral virtues, are one group of personal perfections that are totally within the control of the individual to obtain. They are possible to attain because human beings possess freedom of choice. When choices are repeated, they soon become habits, either good or bad. Good habits are those which are in accordance with the rules for acting well. The moral virtues or goods of character (temperance, courage, and justice) relate to attaining the right end and using the right means to attain that end. Temperance is concerned with pleasure in relation to other goods. It consists of resisting pleasure when it stands in the way of attaining other real goods. Courage or fortitude relates to suffering pain for the sake of attaining the real goods we need. Justice is concerned with the good of others and acting for the common good of the community. For a person to possess justice, he/she must act fairly and respect the rights of others. Temperance, courage, and justice, and prudence (which refers to judging well and making good decisions with regard to conduct) are not existentially separable because one cannot habitually act in the right manner without judging whether or not the means are right. A person cannot act for a right end and a wrong end at the same time. We cannot pursue our happiness effectively without goods of character. The stronger our moral virtue the more likely we are to create a good life for ourselves despite other misfortunes in life because we will be able to make the right choices (Adler, 1984).

Goods of Personal Association

Goods of personal association, such as friendships, family relationships, and love relationships, are one type of external goods or possessions. However, of all the external goods, these goods are largely within the power of the individual to attain. These goods are considered to be among the highest of goods in the scale of goods because human beings are, by nature, social beings and are interdependent. By virtue of being human, these goods are important to people. The goods of personal association are possessed and enjoyed for their own sake, and not merely used as means to other real goods (Adler, 1984).

Economic Goods

All individuals need goods of an economic nature. The quantity of economic goods required for a good life is above that necessary for mere subsistence so that one may do more than just survive, that is, one may also live well and enjoy life. Economic goods refer to consumable commodities, useful services, and the possession of a means to produce wealth. They also include living and working conditions that are conducive to health, medical care, legal services, opportunities for access to pleasures of sense, opportunities for travel, opportunities for access to educational facilities, and enough free time to take advantage of these opportunities (Adler, 1984, p. 48). Not all of these goods are purchasable. Wealth may be attained through many sources (human labour, machines, and raw materials). Money in itself is not a real good; it is a means to wealth. Government involvement is important to ensure environmental protection and public access to an adequate quantity of economic goods (Adler, 1978).

Political Goods

Political goods are those goods relating to government and governance, such as peace, political liberty, freedom of action, and protection from harm. Largely, their attainment is dependent on external circumstances. While a person may influence the attainment of these goods to some extent, their attainment is never wholly within his/her control. To a large extent, the attainment of political goods is dependent on the society in which we live. Political liberty is desirable for its own sake and as a means to happiness (Adler, 1984).

Adler (1981) describes four types of freedom: freedom of choice, freedom of action, moral freedom, and political liberty. Freedom of choice is a natural freedom that all individuals possess even if they are incarcerated. Freedom of action is limited in that one must act within the constraints of justice (p. 141). Moral freedom refers to moral virtue or the disposition to make right rather than wrong choices. Political liberty refers not only to freedom to vote as one chooses but also to the freedom to participate in decisions the outcomes of which affect the individual, in any setting or within any group.

Social Goods

Social goods refer to the equalities specifically as they relate to the dignity of the human person. By virtue of being human, all individuals are equal in terms of their humanness, that is, human beings are equal in terms of their common humanity. Therefore, all human beings are entitled to equality of status, equality of treatment, and equality of opportunity. Differences in natural endowment and wealth can result in certain inequalities; however, these differences are in degree and not in kind. Specific differences in degree may exist, by natural or artificially created differences (Adler, 1981). Adler (1981) stated that we cannot say that people ought to be equal or unequal in any personal respect. Justice must ensure that people possess equality of opportunity, status, and treatment. Government intervention in the way of legislation is usually necessary to ensure equality of opportunity, treatment, and status. There is little the individual can do to ensure these equalities.

Summary

Hemodialysis patients undergo numerous difficulties. Not only do they require treatment three times weekly, but they must also adjust to numerous restrictions in lifestyle. The quality of life of these patients has become of greater concern as society's humanistic concerns have increased. Numerous studies have been carried out in an attempt to measure quality of life. Indices of life satisfaction, self-esteem, functional status, stress, depression, and social support have been used to measure quality of life. The instruments which have been developed have, for the most part, not been tested for their reliability and validity. As yet, there does not appear to be a comprehensive definition and an index for measurement of that which the concept, quality of life, denotes.

In this study, quality of life was conceptualized in accordance with the Aristotelian-Thomistic philosophical theory of the good life. In this theory, happiness is equated with a whole life well-lived (a good life) or happiness in the ethical sense. The good life can only be attained through possession and enjoyment of the real goods which include goods of the body, goods of the mind, goods of character, goods of personal association, economic goods, social goods, and political goods. These goods must also be possessed in the right order and proportion, and the right means must be used to acquire the real goods.

III. METHODOLOGY

Introduction

The purpose of this descriptive exploratory study was to describe the reported quality of life of 10 selected home hemodialysis patients in terms of the Aristotelian-Thomistic philosophical theory of the good life. For the purpose of the study, quality of life was defined as the good life or happiness in the ethical sense. The theoretical framework of the study consisted of propositions about the good life; the real goods, which are possessions and perfections, that are necessary for a good life; and the instrumental means that may be used to acquire each type of real good. A series of individual interviews, using an interview guide, were conducted to gather data relating to the patients' current possession or privation of each type of real good and of the instrumental means to each type of real good. A card sort task was used to assess the importance placed on each type of good by the patients, and the proportion of time spent by the patients in attaining and enjoying each type of good. The interview data were content analyzed in light of the theoretical framework. The rank ordering of the card sort was examined and described.

Setting

The setting of the interviews varied according to patient preference. Seven patients were interviewed in their homes in a private room. Six of these seven patients were interviewed as they were undergoing dialysis in their homes. The remaining three patients were interviewed in a private office in the hospital in which they received their medical care.

Subjects

The sample of the study consisted of a convenience sample of 10 home hemodialysis patients. The subjects were selected from the sampling frame of subjects who met the established selection criteria for inclusion in the study. Each subject was required to have been on dialysis for at least six months, be between 18 and 65 years of age, be free of major systemic diseases (such as diabetes and cancer) other than end stage renal disease, be fluent in the English language, and not have been hospitalized in the month prior to initiation of the study. In order to facilitate access to subjects, only subjects that resided within a 60 mile radius of the city in which the study was conducted were considered.

The sample selected for the study included seven men and three women. The subjects are described in general rather than specific terms to protect their identities. The age of the subjects ranged from 25 to 58 years. The mean age was 40 years. Six of the subjects were married and five subjects had children, ranging in age from 3 years to 30 years. Six patients were working outside of their homes in a variety of occupations: two were blue collar workers, one was a tradesman, one was a farmer, one was involved in retail sales, and one worked as a manager. Of the four subjects who were not working, one was a housewife, one was a student, one had retired, and one was unemployed. All of the subjects had more than 10 years of formal education, with a mean of 13.4 years of formal education. Five subjects identified themselves with specific religious denominations.

The length of time the patients had been on dialysis varied from 9 months to 19 years. The mean time on dialysis was 7.4 years. Prior to initiation of their home dialysis treatment, all of the patients had participated in a training program provided for home hemodialysis patients by the hospital. The causes of renal failure in the patients were as follows: four patients had polycystic kidney disease, four patients had some form of glomerulonephritis, one patient's renal failure was drug-induced, and, with one patient, the cause of renal failure was multifactorial. Four patients had not required hospitalization in the last year; the remaining patients had had from one to three hospital admissions.

Data Collection

Each patient who met the selection criteria for inclusion in the study was contacted by telephone by the investigator to obtain agreement in principle to participate in the study. If the patient agreed to participate, arrangements were made for the patient to be interviewed at a time and place convenient to him/her and the investigator. At the time of the first interview, a written informed consent form was signed by the patient. A total of 21 private interviews, ranging in duration from one to two and a half hours, were held. Two patients were interviewed on three occasions, seven on two occasions, and one on one occasion. The interviews were held approximately one week apart. The variation in the number of interview sessions was necessitated by differences in individual communication patterns. Some patients responded in great depth, while others provided brief responses. When the patient appeared eager and willing to continue the interview after one hour (the approximate time period set for an interview), the investigator allowed the interview to proceed. However, if the patient seemed to be fatigued at any time, the interview was terminated and another appointment was scheduled.

Semi-structured interviews were used to collect data. An interview guide (see Appendix 1) was developed by the investigator for use in the interviews. The questions contained in the guide were basically open-ended and focused on the patients' current possession or privation of each type of real good and of the instrumental means to each type of real good. During the interviews, the subjects were allowed to speak at their own pace; they were encouraged to introduce aspects of their experiences not covered by the interviewer. If a patient introduced a different topic (i.e., a type of good or means to it not under discussion), the order of questions was modified to follow his/her area of concern. The patients were encouraged, where necessary and appropriate, to elaborate on their responses. The patients were asked to provide descriptive demographic data (see Appendix 2) at the end of the last interview, if the required information had not been acquired during the interviews.

A card sort task (see Appendix 3) was used to determine the patients' ordering (or placement of importance) of each type of good in relation to the other goods, and the proportion of time they devoted to the attainment and enjoyment of each type of good. At the end of the first interview, the patients were asked to place the cards (each card described one particular type of good) in order of the importance of each type of good to them, from the most important to the least important. The patients were encouraged to explain the reasons for their rankings. Subsequently, the patients were asked to place the cards in order of the proportion of time they spent in attaining and enjoying each type of good, from most time to least time.

The procedure for data collection followed a standard pattern. The same person, namely the principal investigator, conducted all the interviews and administered all the card sort tasks. Also, the interviews were tape recorded, with the subjects' permission, to facilitate accurate recording of the data.

The Instruments

Questionnaire

The questionnaire used in the study consisted of questions developed by the investigator in light of the Aristotelian-Thomistic philosophical theory of the good life. The questions pertained to the patients' current possession or privation of each type of real good and of the instrumental means to each type of good.

For each type of good, a general question was included which was followed by more specific prompting questions. Questions were also included that related to the amount of time spent by the patients in the attainment and enjoyment of the real goods; this was done to validate the patients' responses to a card sort task which they were asked to undertake regarding the proportion of time they spent in attaining and enjoying the real goods.

The face and content validity of the questionnaire were established with the assistance of two people who were knowledgeable in the area of Aristotelian-Thomistic philosophy and who were also members of the thesis committee. Both persons had to agree (at a 100% level of agreement) that the questions contained in the questionnaire were clear, relevant to the study of quality of life of the home hemodialysis patient, and part of the universe of quality of life viewed in terms of the Aristotelian-Thomistic philosophical theory of the good life. As well, the validators were asked to indicate whether the questions, on the whole, represented a fair sampling of the universe of quality of life viewed in terms of the Aristotelian-Thomistic philosophical theory of the good life. The content of the interview guide was modified numerous times to meet these criteria.

Card Sort

A modified Q sort methodology was used to determine the patients' perceptions of the importance of each type of real good and the proportion of time spent by them in attaining and enjoying each type of real good. A series of cards, each with a definition and an example of a type of real good, were developed. The consistency reliability of the card sort with respect to the patients' ranking of the importance of each type of real good was established through having the patients repeat the card sort task at the end of the last interview. (The card sort task had been administered at the end of the first interview). The time span between the first and last interviews ranged from one to two weeks. In one case, the entire data were collected in one session, so no retest of the card sort task was conducted. The rankings from the first testing were compared with the rankings obtained at the second testing. Percentage agreement between the two testings was calculated. The concordance of the pairs of rankings was 63%; 37% of the pairs of rankings were found to be discordant. Using a Spearman rank order test of correlation, a reliability figure of .998 was obtained for the relationship between rankings obtained during the first and last interviews. Although there was some variability between rankings of the first and second card sorts, the magnitude of the changes in ranking was small, hence, the reliability figure was high. The relatively short period of time that elapsed between the two card sorts may have been a factor that contributed to the observed high degree of consistency since it is possible that the subjects were able to and did recall their first rankings.

The consistency reliability of the card sort with respect to the patients' ranking of the proportion of time spent by them in attaining and enjoying the real goods was also established using the above described test-retest method. The rankings from the first testing were compared with the rankings obtained at the second testing. Percentage agreement between the two testings was calculated. When the rankings given by nine patients on two occasions were compared, 61.1% of the pairs of ranks were found to be concordant, and 38.9% of the pairs of ranks were found to be discordant. Using a Spearman rank order test of correlation, a reliability coefficient figure of .998 was obtained between the pairs of ranks. The magnitude of the changes in ranking that occurred was small. Again, it is possible that there was little change in ranking because the patients were able to and did recall their previous responses.

The face and content validity of the cards used in the card sort task were established through having two persons who were knowledgeable in the area of the Aristotelian-Thomistic philosophy (the same two members who reviewed the questionnaire) review the content of the cards, using the same criteria previously described for the questionnaire. The content was modified until both persons concurred that it met the criteria set for the establishment of face and content validity.

In an attempt to validate the card sort with regard to the proportion of time spent in attaining and enjoying each type of real good, questions relating to time spent in this way were included in the interview guide. The subjects found these questions very difficult to answer. Statistical comparisons of the reported amount of time spent in attaining and enjoying each type of good and the rank order of proportion of time spent in attaining and enjoying each type of good were not possible, since the patients were unable to or did not answer many of the questions during the interview relating to the time spent in this way. For instance, most subjects stated that they were always thinking or using their mind (goods of the mind), and always interacting with others (goods of personal association). As well, many stated that aspects of their moral character were always present or in use but that this was something upon which they did not dwell. Thus, very few patients were able to identify specifically how much time was spent in attaining or enjoying each type of real good.

The types of real goods that patients could describe in terms of the time they spent in attaining and enjoying them were goods of the body and economic goods. The time spent in attaining and enjoying goods of the body ranged from two hours to "all day and all night". The time spent in attaining and enjoying economic goods ranged from "not much" to "most of the time".

A few inconsistencies were found when the data from the questionnaire were compared with data from the card sort. For example, one individual stated that, in terms of attaining and enjoying the real goods, he spent 12 hours a day on goods of the body, 8 hours a day on economic goods, almost all the time on goods of the mind, goods of character, goods of personal association, and social goods. However, in the card sort task, economic goods were ranked highest, followed by goods of character, and goods of the mind. In light of such inconsistencies, it is difficult to draw a conclusion regarding the concurrent validity of the card sort, especially given the nature of the data gathered in the interviews using the questionnaire.

Pilot Study

A pilot study was conducted involving one home hemodialysis patient. The purposes of the pilot study were to familiarize the interviewer with the questionnaire, to ensure that the questions were clear, and to test the suitability of the cards to be used in the card sort task. No changes were made in the instruments as a result of the pilot study. Thus, the data obtained in the pilot study were used with data obtained from nine other patients to answer the research questions.

Ethical Considerations

Initial contact with the patients was made by telephone by the investigator. The purpose of the study was explained to the patients and an initial verbal agreement to participate in the study was obtained. Interviews were scheduled for mutually convenient times. The patients were informed that their perceptions about their quality of life would be under study and that they would be interviewed privately, approximately three times, at weekly intervals. All of the subjects were informed that the information they provided would be treated as confidential material and that no names or identifying data would appear in any report of the study. The patients were informed that they were free not to participate in the study, to withdraw from the study at any time, and to refuse to answer any question and, in doing so, would not be jeopardizing their care. At the time of the first interview a written consent form was signed and witnessed (see Appendix 4). A copy of the consent form was given to each subject for future reference.

Upon completion of the project, all of the tapes were erased. However, coded copies of typed transcripts were retained for future reference. Approval to conduct the study was obtained from the Division of Nephrology and the research review committees of the hospital involved.

Data Analysis

All of the raw data from the interviews were transcribed. Content analysis was carried out in light of the Aristotelian-Thomistic philosophical theory of the good life. The patients' verbal responses about their present lives were carefully reviewed. Categories and subcategories relating to the patients' possession or privation of the real goods, and categories and subcategories relating to the patients' possession or privation of the instrumental means to the real goods were established. The patients' statements were segmented into analytic units according to the established unit of analysis and distributed over the established categories and subcategories of possession and privation of the real goods and instrumental means. A unit was designated as relating to possession or privation of the real goods or instrumental means, by the investigator, in light of the patients' reports, the definitions of the terms, and the Aristotelian-Thomistic philosophical theory of the good life.

Unit of Analysis

The unit of analysis was a verbalization by a subject which referred to an aspect of the present life of that subject. An unit was a statement, statements, question, group of words, or single word that was directed by the subject to the investigator. An unit consisted of either an explicit or implicit reference to the possession or privation of a real good, or the possession or privation of an instrumental means to a real good. An unit ended and a new one began when the subject referred to a real good or instrumental means that was different from the one that he/she had been describing, or repeated his/her reference to either a real good or instrumental means he/she was describing.

Categories of Analysis

Two major categories of analysis were established: possession or privation of real goods and possession or privation of instrumental means to the real goods. The definitions of these major categories and some of the subcategories relating to the dimension of real goods were based on the writings of Adler (1941, 1965, 1971 1980, 1981, 1984, 1985) as interpreted by the investigator. The definitions of the remaining subcategories relating to the dimension of real goods, and of the subcategories relating to the dimension of instrumental means were inductively generated from the data in light of the definitions that had been established based on the writings of Adler as interpreted by the investigator.

I. Possession or Privation of the Real Goods (Constitutive Means)

Real goods are those goods that meet the natural needs of human beings and are necessary to have a good life. The categories of real goods include goods of the body, goods of the mind, goods of character, goods of personal association, social goods, political goods, and economic goods. Possession of the real goods refers to a person's ownership or possession of real goods such as certain attributes, knowledge, skill, or objects to the extent required to have a good life. Privation of real goods refers to the lack of possession by a person of the real goods to the extent required to have a good life.

A. Goods of the body are those perfections that relate to a person's bodily condition and functioning, such as health, vigor, vitality, and pleasures of sense.

   1. Health refers to the structural and functional integrity of a person's body or body parts, including general health, freedom from pain, and mobility.
   2. Vigor is the physical strength or energy of a person's body.
   3. Vitality refers to the growth and development of a person's body or body parts (e.g., hair, nails, skin) and includes general anabolism, as opposed to catabolism, of the body.
   4. Pleasures of sense are the agreeable sensations a person perceives through the senses of sight, hearing, taste, smell, and touch.

B. Goods of the mind are those perfections that involve a person's intellect, such as knowledge, understanding, mental abilities, spirituality, and pleasurable feelings.

   1. Knowledge and understanding refer to a person's comprehension of information and truths about various objects.
      a. Knowledge and understanding related to treatment and illness refer to a person's comprehension of the disease process and treatment involved in end stage renal disease.

b. Knowledge and understanding related to self refer to a person's comprehension of aspects of his/her own body, mind, and character.

c. Knowledge and understanding related to other people refer to a person's comprehension of aspects of other persons.

d. Knowledge and understanding related to life situations refer to a person's comprehension of a wide variety of situations that occur in life. It includes knowledge regarding work, the hospital environment, and life in general.

2. Mental abilities refer to the abilities which result through a person's use of his/her mind or intellect and includes abilities such as concentrating, remembering, thinking, hoping, learning, communicating, judging, and creating.

a. To concentrate is the ability to center thought on one point or topic for a length of time.

b. To remember is the ability to retain information and recall events from the past.

c. To think is the ability to consider, muse, and meditate.

d. To hope is to desire some future benefit.

e. To learn is the ability to acquire knowledge through formal or informal means.

f. To communicate is the ability to impart or receive information from another person.

g. To judge is the ability to make prudent decisions and to employ common sense.

h. To create is the ability to make or produce an original object, generally referring to an object of art.

3. Spirituality refers to a person's state of faith or beliefs about God or a higher being.

4. Pleasurable feelings are the positive sentiments a person experiences about various people, things, or objects.

    a. Feelings related to dialysis and illness are the feelings a person has that relate to end stage renal disease, its manifestations, and its treatment.

    b. Feelings related to self are the feelings a person has about his/her body, mind, or character.

    c. Feelings related to other people are the feelings a person has about other people or groups (such as friends, family, health professionals).

    d. Feelings related to life situations are the feelings a person has that relate to life situations, such as work, the hospital environment, and life in general.

C. Goods of character are a person's moral perfections such as those of temperance, justice, and fortitude.

1. Temperance refers to the resistance of pleasure when it stands in the way of attaining other real goods.

2. Justice refers to acting fairly toward other people, respecting the rights of other people, and acting for the common good of the community.

3. Fortitude is the moral strength or willpower to overcome adversities of all sorts, and the courage to suffer pain for the sake of attaining other real goods.

4. Other moral goods are aspects of a person's moral character other than temperance, justice, or fortitude (e.g., honesty, persistence).

D. Goods of personal association are possessions in the form of a person's relationships with people, such as friends, family members, spouses, health professionals, and peers.

1. A friendship is a mutual, caring relationship that exists between two people who are not related to each other (by marriage or blood) and who act justly toward one another.
2. A family relationship is a relationship that exists between a person and his/her relatives (e.g., parents, siblings, children, grandchildren).
3. A marital relationship is a type of friendship that exists between two people who have made a legal or verbal commitment to each other. It is usually characterized by a strong feeling of affection, devotion, and caring between the two people involved who would do whatever may be necessary to improve or enrich the life of the other.
4. A professional relationship is a relationship that exists between a person and a health professional (e.g., doctor, nurse, social worker).
5. A peer relationship is a casual type of relationship that exists between a person and others in the community and is one in which one or both parties do not feel particularly close to one another.

E. Social goods are those possessions that relate to human dignity, such as equality of opportunity, equality of treatment, and equality of status.

1. Equality of opportunity is the circumstance where people have the same or equal initial conditions when beginning an activity.
2. Equality of treatment is the circumstance where people are treated equally with respect to the fulfillment of their needs as human beings.

3. Equality of status is the circumstance where a person's standing or position in society is considered to be the same or equivalent to others in terms of his/her humanness.

F. Political goods are those possessions that relate to government and governance of a person, such as political liberty, freedom of action, and protection from harm.
   1. Political liberty is the freedom to vote as a person chooses and to participate in decisions, the outcomes of which affect the person.
   2. Freedom of action refers to the liberty to act as a person pleases within the constraints of justice.
   3. Protection from harm refers to the measures taken or that are in place that ensure a person's safety.

G. Economic goods are those possessions or financial resources that a person needs in order to have a good life, such as free time, wealth, a means of subsistence, working and living conditions conducive to health, opportunities for self improvement, and availability of health services.
   1. Free time is the (duration of) time available that is not devoted to work that may be used to improve oneself or society.
   2. Wealth is a financial or economic resource that results in prosperity, and consists of such possessions as money, capital, and material belongings.
   3. Means of subsistence refers to the work done or ways used to earn a living.
   4. Working conditions are the circumstances conducive to health under which a person works.

5. Living conditions are the circumstances conducive to health under which a person lives and travels.
6. Opportunities for self-improvement refer to the external resources people have available to them that may assist them in the enhancement of their skill, knowledge, or character (e.g., libraries, adult education courses).
7. Availability of health services refers to the existence of health services and ~~ease~~ of access to health care.

II. Possession or Privation of Instrumental Means to the Real Goods

Instrumental means are the actions performed by human beings to obtain the real goods or the set of circumstances that operate to bring about possession of the real goods. The major categories of instrumental means are as follows: physiological, mental, social, economic, and environmental. Possession of an instrumental means refers to a person's use of or involvement of an instrumental means to the extent required to attain a real good. Privation of an instrumental means refers to the lack of an instrumental means, that is, an instrumental means is not available to the extent required to attain a real good.

A. Physiological means are those means that directly involve a person's bodily functioning or action upon a person's body or body parts. They include nourishing activities, treatments, and state of health.
   1. Nourishing activities refer to those activities a person naturally carries out on a regular basis that serve to feed or sustain the body and include resting and sleeping, exercising, and eating and drinking.
      a. Resting and sleeping refer to the acts of relaxing, sleeping, and not moving.

   - b. Exercising refers to the act of using the body's muscles or exerting the body.
   - c. Eating and drinking refer to the consumption of various types and quantities of food and fluid (including alcohol).

2. Treatments refer to the prescribed and non-prescribed technical or artificial means a person uses to augment the nourishing activities.
   - a. Prescribed treatments are those remedies that are suggested or ordered by a health professional (e.g., doctor, nurse, social worker) and include dialysis treatment, medications, and other medical treatments.
      - i. Dialysis treatment is a medically prescribed extracorporeal treatment that removes excess fluid, electrolytes, and nitrogeneous waste products from the blood of a person with end stage renal disease.
      - ii. Medications are chemical or biological substances that are prescribed by a licensed physician for the prevention, cure, or treatment of a disease.
      - iii. Other medical treatments are methods of managing symptoms, preventing disease, or promoting health (other than by dialysis or the administration of drugs) that are prescribed by a health professional, such as transplantation and blood transfusions.
   - b. Non-prescribed treatments are those remedies that are initiated by a person without the advice of a health professional (e.g., non-prescribed drugs, home remedies).

3. State of health refers to the condition of a person's body or body parts.

B. Mental means refer to those means that involve a person's mind or intellect and will and include cognitive strategies, and attitudes and approaches.

1. Cognitive strategies refer to the methods used by a person to obtain information or facts and to come to know and understand them (e.g., reading, observing, inquiring, reflecting, thinking).
2. Attitudes and approaches refer to a person's relatively enduring feelings, beliefs, and behavioral tendencies toward people, groups, objects, or ideas.

C. Social means are those means that involve or arise from interaction between persons and include maintaining contact, receiving help, and giving help.

1. Maintaining contact refers to a person's attempt to continue to interact or communicate with people for purposes other than help.
2. Receiving help refers to a person's receipt of assistance from others in the form of support, encouragement, services, or resources.
3. Giving help refers to a person's offer or provision of assistance to other people in the form of support, encouragement, services, or resources.

D. Economic means are those means that are financial in nature and include wealth, work, and time.

1. Time is a span of clock time available or used for tasks or activities.
2. Wealth refers to money, property, and material possessions.
3. Work refers to the labor performed by a person for remuneration.

E. Environmental means are the physical conditions in which a person lives and works.

Coding Reliability

Two coders independently coded a random sample of 10 pages from the interview transcriptions to assess the reliability of the investigator's coding of the data. The units were demarcated on the sheets to be coded. The coders were provided with the definitions of the categories of analysis and asked to code the demarcated units according to the definitions. After the training of the coders and several trials of coding, an 81% agreement on the coding of the demarcated units was obtained between one coder and the investigator, and an 84% agreement between the other coder and the investigator.

The investigator also recoded 10 randomly selected pages of data three weeks after the initial coding was completed to assess intrarater reliability of the coding of the data. There was 93% agreement on the coding of the units.

Summary

A study examining the reported quality of life of patients receiving home hemodialysis treatment was conducted. The Aristotelian-Thomistic philosophical theory of the good life was used for the theoretical framework of the study. According to this theory, a person must possess and enjoy all the real goods in the right order and proportion and use the right instrumental means to these goods in order to have a good life. A convenience sample of 10 adult, medically stable, home hemodialysis patients was studied to determine the patients' reported current possession or privation of each type of real good and of the instrumental means to each type of real good. The subjects were interviewed individually for a total of approximately three hours each. One to three interviews were held with each subject. The interviews were semi-structured in that an interview guide was used. A card sort task was used to determine the importance of each type of real good to the patient and the proportion of time spent by the patient in attaining and enjoying each type of good. The data were content analyzed according to the theoretical framework and categories of analysis were established.

IV. PRESENTATION OF THE FINDINGS

Introduction

The findings of this study on the reported quality of life of selected home hemodialysis patients are presented in the following order. The subjects' reports pertaining to the possession or privation of each type of real good are described first. This is followed by a presentation of the findings pertaining to the subjects' reports regarding possession or privation of the instrumental means to each type of real good. Finally, the results of the card sort task with regard to the order of importance of each type of real good as reported by the patients and the amount of time spent by the patients in the attainment and enjoyment of each type of real good are presented. Specific details that could potentially identify the subjects have not been provided in order to protect their identities.

Possession or Privation of the Real Goods (Constitutive Means)

Possession of real goods refers to the fact that a person possesses, to the extent required to have a good life, one or more of the types of real goods or those things that meet the natural needs of human beings and are necessary in order to have a good life. This may be contrasted to the state of privation of real goods where a person lacks, to the extent required to have a good life, one or more of the types of real goods. In this study, the possession or privation of each type of real good by ten patients with renal failure who were receiving home hemodialysis treatment were examined. Data relating to the patients' possession or privation of each type of real good are presented in the following pages.

Goods of the Body

Goods of the body refer to those perfections that relate to a person's bodily condition and functioning, such as health, vigor, vitality, and pleasures of sense. All of the subjects indicated that they possessed a fair degree of health. Only two subjects indicated that they had an adequate amount of vigor; many complained about their low level of energy. Seven subjects indicated that they had good vitality, and nine indicated that they enjoyed pleasures of sense. Table 1 depicts each patient's possession or privation of these real goods.

Health

Health refers to the structural and functional integrity of a person's body or body parts. It includes general health, freedom from pain, and mobility. The subjects were asked about the physical condition of their body and how it functioned. Seven of the 10 patients stated that they believed that their health was good or very good in spite of the fact that they had renal failure. Two patients stated that it was "not too bad", and a third stated that her health was "okay but not normal". Two of these individuals also had another chronic disease that may have affected their health. As if to substantiate their reports regarding their health, several patients reported that they had not been hospitalized for some time, that they had taken little time off from work for illness in the preceding years, and that their blood biochemistries were good. Several of the patients compared their present state of health to their past health and still concluded that their present health was good. One subject aptly stated, "I think basically I would say that my present condition is quite satisfactory and allows me to enjoy life".

At the time of the interviews, all but one patient indicated that their weight had been stable. The remaining patient described a slow weight loss of 25 pounds which he had experienced since starting dialysis eight years previously.

Table 1

Possession or Privation of Goods of the Body

Subject Number	Goods of the Body Health (according to definition)	Vigor	Vitality	Pleasures of Sense
1			X	X
2				X
3				
4			X	X
5			X	X
6				X
7		X	X	X
8			X	X
9		X	X	X
10			X	X

"X" indicates possession of the real good to the extent required to have a good life, as judged by the investigator in light of the Aristotelian-Thomistic philosophical theory of the good life.

No "X" indicates privation of the real good to the extent required to have a good life, as judged by the investigator in light of the Aristotelian-Thomistic philosophical theory of the good life.

In relation to their mobility, all the patients stated that they had free movement of their limbs and many of them said that they were active physically. Two patients complained of a "restless leg" syndrome that occurred during dialysis or at night. This refers to a nerve irritability that is a common manifestation of renal failure.

Most of the patients initially stated that they had no pain. One patient stated that the "only pain I ever have is mental pain". However, all but one patient went on to describe minor discomforts. Two patients complained of headaches associated with dialysis, one complained of muscle cramps associated with dialysis, two complained of discomforts related to another chronic ailment, two reported muscle aches, and one patient said that she had sore feet. Two patients identified discomforts associated with venipunctures for dialysis; one was unable to insert needles without local anesthesia because of the pain and another said that he had occasional discomfort when he "missed a needle".

All of the patients reported some disturbance of their elimination patterns. Seven patients said that they had little or no urine output. Six patients reported problems with constipation, a result of the administration of aluminum hydroxide or iron preparations, and a reduced fluid intake. Nausea and vomiting were not identified as a problem by any of the subjects. The patients stated that any current episodes of nausea or vomiting were associated with flu or other illnesses, excess fluid removal on dialysis, and alcohol consumption. Four patients thought that they lost less fluid through perspiration than other people. The other subjects thought that they perspired normally or perspired heavily with physical exertion.

Several of the subjects complained of dry hair and skin. Three patients reported that they had dry hair, and three stated that their hair was thinner than it had been previously. Six people complained of dry skin and three patients complained of itching. One woman pointed out the numerous bruises on her body which had occurred spontaneously or as a result of minimal trauma.

Most of the subjects indicated that they had relatively normal sensations. Visual acuity was reported as good by all subjects; however, one patient knew that she had cataracts and said that she occasionally had blurring of vision. Another patient stated, "My eyes started getting bad right after dialysis, and they actually change during the day. In the morning, when I get up, I can see very good, [sic] but the day before I go on dialysis, like this afternoon, I was having trouble and I don't see nearly as well. I suppose it's because of the wastes". Seven patients reported that their hearing was good; one person had a long-standing bilateral high frequency hearing loss, a result of recurrent otitis. Two persons described their unilateral hearing deficits. All patients believed that their sense of touch was normal. All but two patients reported that their sense of taste was normal. One woman stated, "I can taste things but not everything tastes terrific to me anymore". Another man stated, "When I first got on the machine ... I couldn't taste nothing [sic] ... [now] I get this funny taste and I get a funny feeling or something ...". All subjects, but one, who suffered from sinusitis, said that they had a good sense of smell. Generally, most of the subjects felt that they were quite aware of what was going on around them. However, two men stated that, after dialysis, they were not "quite as sharp".

In relation to sexual functioning, only one man reported that there had been no change in his sexual functioning as a result of his illness. He stated, "Everybody says it slows you down, and you read it in that stupid book; then you put that in your head plus if you weren't too active [sexually] before, you might not be at all now or not very much anyway. But I never let that worry me". Two women stated that their sexual activity was "practically nil"; they reported that they no longer had any desire for sex. Three younger men reported a decrease in sexual activity since starting dialysis. One man estimated that he was "only 50 or 60 or 70% as sexually active" as he had been prior to the onset of his illness. He also reported that, after dialysis, he did not "feel like engaging in sex". However, he said that ten hours later, "It's not too bad". One man declined to discuss his sexual functioning and one woman stated that it was not an area of concern for her since she was not married.

Vigor

Vigor refers to the physical strength or energy of a person's body. Only 2 of the 10 subjects thought that they had enough energy to do the things they wanted or needed to do. The remaining patients made the following types of comments: "My stamina is not there"; "I'm tired at times"; "I'm not so efficient. I sit down and I rest, and then I get up and do something and I sit down and rest"; "I have times when I can't do very much"; "I have the energy to work full-time but no more than enough". The two patients with good vigor had very active, busy schedules. Six of the patients reported that they had the energy to work full-time; all of the subjects stated that they had the energy to care for their own personal needs, including dialysis. Two men reported being active participants in sporting activities. One woman needed assistance with housework. Several patients identified that their energy level was dependent on what they wanted to do. If they had no desire to perform an activity, they found that they usually did not have the energy to carry it out. In terms of physical strength, six patients stated that their muscle strength was good. Others stated that their strength was variable, not as good as it had been previously, or poor.

Vitality

Vitality refers to the growth and development of a person's body or body parts. Many of the patients reported a deterioration of their bodies before and around the time they first started dialysis but indicated that there had been no recent deterioration. In relation to parts of their bodies, two patients stated that their hair grew more slowly and three patients noted a tendency to heal slowly.

Pleasures of Sense

Apart from a few exceptions, all of the subjects enthusiastically described the pleasures of sense that they experienced, that is, the agreeable sensations they perceived through the senses of sight, hearing, taste, touch, and smell. One man stated, "Before, I really took stuff for granted and now you appreciate it a little bit more". Only one woman did not expound on her pleasures. In contrast to the expositions of the other subjects, she stated, "You don't really think about it when you're doing it" and "If it's noticeable and catches my eye, I guess so" [enjoy scenic views]. One woman stated that she did not obtain much pleasure through her sense of smell. In relation to pleasures derived from the sense of touch, only three of the subjects reported that they received such enjoyment from sexual activity. Two patients reported that they did not obtain pleasure through their sense of taste; one man stated that he only ate because he had to and a woman noted that "the taste isn't what it used to be". Nine patients reported receiving pleasures from sights, particularly those related to nature. Vivid descriptions of animals, trees, and architecture atested to the pleasures of sense the subjects' derived from the sense of sight.

Goods of the Mind

Goods of the mind are those perfections that involve a person's intellect and include such things as knowledge, understanding, mental abilities (e.g., to remember, to concentrate, to create), spirituality, and pleasurable feelings. For the most part, all of the patients indicated that they possessed knowledge and understanding related to their illness and treatment. It was interesting to note the depth, accuracy, and current state of knowledge that the patients possessed in relation to their disease and treatment. Five patients indicated that they had good or normal mental abilities. It should be noted that the patients suggested that impairments or deficiencies in mental abilities (such as inability to create things) were, for the most part, not related to their illness or treatment. Four patients indicated that they possessed a faith in God or a higher being. Feelings, both pleasurable and negative, were expressed by all patients on a wide variety of topics. Table 2 depicts each patient's possession or privation of the goods of the mind.

Knowledge and Understanding

Knowledge and understanding refer to a person's comprehension of information and truths about various objects. The patients' possession or privation of knowledge and understanding related to their treatment and illness, themselves, other people, and life situations are described.

Knowledge and Understanding Related to Treatment and Illness.

Generally, all of the patients thought that they had a good comprehension of their disease process and the treatments involved in end stage renal disease. They were all able to identify the origin of their renal disease and were well versed in the dysfunctions experienced by patients with renal failure. For instance, several patients identified sexual dysfunction, itching, and anemia as common manifestations of renal failure. One young man spoke knowledgably about fluid shifts and electrolyte imbalances. Another man stated, "I'm probably very aware of my dialysis condition and the kidney disease and how to make life better". Yet another man said, "It would be incredible if I didn't know a fair amount about my disease and all the ramifications in terms of course and therapy". It was interesting to note that three patients spoke knowledgably about aluminum

Table 2

Possession or Privation of Goods of the Mind

	Goods of the Mind			
Subject Number	Knowledge & Understanding	Mental Abilities	Spirituality	Pleasurable Feelings
1	X	X	X	
2	X			
3	X			
4	X	X	X	X
5	X			
6	X	X	X	X
7	X		X	X
8	X	X		X
9	X	X		X
10	X			

"X" indicates possession of the real good to the extent required to have a good life, as judged by the investigator in light of the Aristotelian-Thomistic philosophical theory of the good life.

No "X" indicates privation of the real good to the extent required to have a good life, as judged by the investigator in light of the Aristotelian-Thomistic philosophical theory of the good life.

toxicity and dialysis dementia, conditions which have been recognized as problems only in the recent past.

All of the patients spoke intelligently about their dialysis treatment and some of them discussed alternative treatments. Explicit descriptions of dietary restrictions were provided by many of the patients. In one case, a man demonstrated an understanding of his individual dietary regimen as well as the regimen of other patients when he stated, "I know that's not common with kidney patients because most patients don't have output, and that's probably the number one priority with them is the fluid intake [sic], but with me it isn't". All of the subjects named one or more of their medications and many patients volunteered information relating to the actions and side effects of their drugs. Several patients seemed to be harboring some misconceptions. One woman used the wrong term for dialysis concentrate, another woman was mistaken in the frequency of exchanges required with continuous ambulatory peritoneal dialysis, and one patient talked about brain cells dying while a person was on the machine. Another patient stated that a specialist told her that she was allergic to the machine (which is highly unlikely) but that "I really don't know the process". Although these comments indicate a lack of knowledge and understanding on the part of several of the subjects, most of the data obtained indicated that the patients possessed a good understanding of their illness and its treatment.

Knowledge and Understanding Related to the Self. During the interviews, only certain aspects of the patients' comprehension of aspects of their own body, mind, and character were addressed. However, most of the patients, at some time during the interviews, specified a numeric value for one of their blood chemistries, indicating their knowledge about this aspect of their own bodies. One man was able to detect minute physiological changes associated with changes in his blood chemistry values. All of the subjects indicated that they were aware of their personal strengths and weaknesses, but three patients seemed unwilling or were unable to describe them. These latter people merely commented, "I know what I can and can't do", or "I don't know". Another man very aptly revealed that he knew himself when he stated, "I think I probably have gone through as traumatic a life as anybody's life, probably more so, and I've become a coper. I've managed it very well. I've faced a lot of problems and it comes back to just being a survivor, being able to cope".

Knowledge and Understanding Related to Other People. Several patients made statements indicating that they understood how other people felt. One older man stated, "I've never had any problems . . . [but] I can put myself into the position of a younger man who has a life ahead of him and who wants to be active, wants to do things, and resents being tied to the machine". Two other patients indicated that they could understand the desperation of one renal failure patient who had recently advertised his desire to purchase a kidney. One man stated that he could understand how difficult it must be for a physician to request permission for an organ donation from a family who had just learned of the death of a loved one.

Knowledge and Understanding Related to Life Situations. All of the subjects reported that they had a fairly good understanding of life situations. Several patients provided examples of situations that they had come to understand as a result of the experiences they had had or others around them had had. When asked about life situations relating to organ donation, all of the subjects were able to discuss the issue.

Mental Abilities

Mental abilities refer to the abilities which result through a person's use of his/her mind or intellect. The patients' possession or privation of the following abilities are presented: to concentrate, to remember, to think, to hope, to learn, to communicate, to judge, and to create.

To Concentrate. All of the patients stated that they were able to concentrate fairly well, that is, to focus thought on a topic. One man stated that he could concentrate but could not retain the information. Another man indicated that he believed his concentration would improve if he were not on dialysis.

To Remember. Five patients reported that they were able to remember, that is, to retain information and recall events from the past. However, they said that they had occasional lapses of memory. One man stated, "It's always been short so there's not much difference". Another man reported that his memory was not as good as it had been in previous years, but "it's no worse and no better than most people in my age group". Two men attributed their decline in memory to the aluminum hydroxide that had been prescribed for them as a phosphate binder.

To Think. All of the patients reported that they had the ability to think, that is, to muse, to contemplate, to consider, and to meditate. Many of the patients reported that they tended to use dialysis time for thinking. Two men stated that they had little time for thinking; one of these men remarked that the only time he had available for thinking was the 10 minutes before he went to sleep.

To Hope. Six patients reported that they hoped for various things; the others denied having hopes. One man hoped to win a lottery. Another patient hoped to be famous. Four subjects stated that they hoped for kidney transplants. One woman stated, "I hope that everything will go well for us and that someday I could [sic] get a transplant". Another man stated, "I fantasize a lot about getting off this [machine] and going to pursue my career ...".

To Learn. All of the patients reported that they had the ability to learn or to acquire knowledge readily through formal or informal means. Most of them cited their learning to carry out their dialysis treatments as an example of their ability to learn. One woman stated, "I thought I'd never learn how to do this. In less than two months I got the machine to go home". One man described himself as inquisitive and eager to learn. Another man stated that he did not learn as readily as other people, but said, "It is not a problem".

To Communicate. The reports of five of the patients indicated that they possessed the ability to communicate, that is, to impart or receive information from another person. One man stated, "I have problems with people not agreeing with my opinions quite often, but I am quite able to make myself very clear". Three other people, two men and one woman, stated that they had difficulty expressing some of their feelings to others. One man said, "I have these feelings, but I have a hard time letting other people know what they are". Another man reported that he had difficulty responding in "the most responsive way". This man also stated that he found it difficult to communicate in a group setting.

To Judge. The reports of all but one of the subjects indicated that they possessed common sense and reasonably good judgement. One man stated, "I think that I have too much common sense sometimes and I think I'm just too practical ... for my own good". He thought that there were times at which he should "go for the wild thing". Two subjects stated that they were not in positions (either at work or home) where they were expected to make decisions. However, they thought that the decisions that they did make were sound. One said, "I think I take more of my time now to judge something. I look at it from different points of view now". The patient who did not believe that she had good judgement stated, "I just never know really what to say; I always use this 'I don't know, I don't know'". Then she went on to say, "I try to make the decision on my own ... lots of time I feel sorry what I've made [sic] because it wasn't a very smart decision ... Things don't work out the way I usually think it's going to work out when I make a decision. Then I learn the hard way".

To Create. Three of the subjects reported that they were engaged in some creative endeavors. One man was very creative; he was involved in the production of several different types of art forms. Two women stated that they knitted and produced crafts. The remaining patients did not believe that they were able to create things.

Spirituality

Spirituality refers to a person's state of faith or beliefs about God or a higher being. Although five of the patients indicated that they belonged to a specific religious denomination, not all of these people had great faith in a higher being. One man, who identified himself as being a Catholic, stated "I guess I have probably lost some faith in the supreme being [as a result of the illness]". Another patient said, "I don't know why God makes all the good people sick, and all the rotten people get to live a good life". Four patients expressed ambivalent feelings about their faith; one of these patients referred to himself as "an old fashioned rationalist". Another man indicated that he believed that he, not God, controlled his destiny. One man reported that he possessed a very deep faith.

Pleasurable Feelings

Pleasurable feelings refer to the positive sentiments a person experiences about various people, things, or objects. A great deal of data were obtained from the subjects about their feelings. Not all of the feelings reported by the patients were pleasurable or positive in nature. The feelings reported by the patients that were not pleasurable in nature are referred to as negative in this study. Since negative feelings are related to the privation of pleasurable or positive feelings, a real good, they are discussed along with the positive feelings. Both positive and negative feelings are described under the headings of feelings related to dialysis and illness, feelings related to self, feelings related to other people, and feelings related to life situations.

Feelings Related to Dialysis and Illness. A few patients expressed pleasurable feelings about their dialysis. One man stated, "I love it because it's keeping me alive. I'm here now and it keeps me here for that chance to have that kidney". Several of the other patients expressed similar feelings. Another man stated that he was happy about his illness when he was able to help another dialysis patient learn from his experiences.

It was more common for patients to express negative feelings rather than pleasurable feelings. The patients indicated that, although they were unhappy about their condition, they were learning to live with it. For instance, one man stated, "I don't think one would be happy to be on dialysis but I do not consider it a terrible cross to bear. It is a cross to bear but it is no more a cross to bear than many other people in my age group [50 to 60 years] who have other crosses to bear. It's a painless treatment; it's a good quality of life". One man stated, "Happy? You must be joking! Nobody feels happy. It's just that you have to accept it in your life".

A few subjects talked about their anger and frustration about the illness. One man stated, "I get so frustrated I might take a run and say to hell with it ... but not so angry that I would pull the plug on myself". Another man stated with frustration, "I just think there is no more prison in this world". In another case, a man asked, "Why does everything always happen to me?"

Several patients reported that they felt fearful. In particular, the needles used for dialysis frightened at least three of the subjects. One woman expressed her fear of pain from venipunctures and stated, "The thickness of the needle - I think turns everyone off". Although most of the patients denied that they still had fears about their dialysis or the needling procedure, one man commented that the time he spent preparing his dialyzer was useful since he could prepare himself for insertion of the needles. One man expressed a fear of being hospitalized; he was so afraid of hospitals, that he was considering refusing kidney transplantation because he would need to be hospitalized for the procedure. Another patient expressed a fear of the effect of aluminum (from phosphate binders) on his mind.

Several patients expressed feelings of sadness in relation to their illness and its outcomes. In one situation, a man said that he had been told by the medical staff that it was unlikely that his life expectancy was longer than ten years. Based on that information, he decided that he would never marry. He was determined not to be a burden to another person. He stated that he now felt somewhat sad about having no one with whom he could share his problems. Another woman expressed some sadness about her decrease in libido.

Two patients expressed resentment about their medications and diet. In relation to her diet, one woman stated that she resented "drinking nothing" while others were having a good time. She also spoke of "cheating" on her "horse pills" (referring to the phosphate binding medication). Her tone of voice seemed to indicate that she also resented taking these medications.

Feelings Related to the Self. A number of patients expressed feelings about their own bodies and minds. In relation to her feelings about her body, one woman stated that she was unhappy about not being like a "normal person" anymore. Another woman remarked that she felt embarrassed about her graft which looked "terrible"; she often wore long sleeves to hide it when she went out. One woman expressed pleasure in relation to her knowledge about her condition. She commented with pride, "I used to be such a dummy ... and now it seems I know so much about phosphorus ... I feel intelligent. You know so much more than what [other] people know and it makes you feel good inside when you know what you're talking about".

Feelings Related to Other People. The subjects frequently commented on their feelings in relation to other people. In particular, many patients expressed their pleasurable feelings about the medical and nursing staff. Most of the patients were very appreciative: "The nurses in the dialysis unit are fantastic", "The nurses and technicians couldn't be more helpful", and "[they are] extremely competent, kind, considerate, and certainly everybody is willing to listen and to be helpful".

A number of subjects made brief comments about their feelings about their spouses, families, and friends. Only one man openly expressed his feeling of love for his wife. He indicated that she was the only reason for him to continue living; he said that, if she died, he would commit suicide. Two patients expressed their love for their children. Most of the other feelings described by the patients in relation to their families, friends, and spouses centered around their appreciation of these people, and of the help they received from them.

Several patients expressed negative feelings, such as resentment and anger, about the hospital staff. One patient thought that the nursing staff in the home dialysis unit were generally too busy to really talk to her except to ask her how she felt. Another man expressed resentment about having to prepare his dialyzer during the training period; he thought that the nursing staff should have been more cooperative and prepared the dialyzer for him when he was tired. Two patients reported that they resented the nurses telling them what to expect, when they did not know "what it's really like". One man stated that he was "still pissed off at that doctor" for not telling him that he would be infertile once renal failure developed. He indicated that he and his wife would have had another child early in the course of his illness had they been aware of this fact. In one case, a man angrily stated, "There are people who shouldn't be doctors or nurses". Although he did not elaborate on the incident(s) that resulted in these feelings, he indicated that he thought that these staff members were "uncaring" and made reference to the fact that they belonged to another ethnic group. However, this man also expressed some very positive feelings about other staff members.

Several patients reported their feelings of hostility or sadness about the patients they had seen or met in the hospital. Most of these feelings were not pleasurable. One man stated that he did not care what happened to any of the other patients, and that he could not stand "listening to people complaining about their ills". Two men expressed sadness; for example, one man said, "I've seen a lot of young patients come into the hospital and they just had no desire at all to live. It's very sad to see that in young people". He went on to explain why he did not attend any patient group meetings: "I guess I just did not want to be associated with this group of people. There were copers in there but some that did not cope and I felt sad for some of those people". Another patient indicated that it upset him to see other patients who were not doing well; he avoided the hospital for this reason.

Feelings Related to Life Situations. Feelings about life situations include feelings expressed by the patients on a wide range of topics from life and death to eating, drinking, and smoking. All of the patients expressed some feelings about life, death, and dying. One man stated, "I have no fear of death. And many times I would have welcomed it. The fear is of dying, painful or slow dying. What I pray for is a quick heart attack which finishes me off with nobody around to ...". Another older woman stated, "When it's time to go, it's time to go, I guess". This feeling was expressed on a number of occasions by other patients. However, some of the patients had very different feelings. A young patient stated, "I worry about my own death especially when I feel so rotten and on the machine all the time. You think so many things can go wrong". Another woman reported that she worried about what her family's life would be like if she died. One man stated, "Death saddens me a little more than it did - particularly [of] younger people. It really bothers me".

Some of the other feelings that the patients expressed related to other life situations were anger relating to a current news item, anger about wastage of public funds, and anxiety about public speaking. These feelings were each expressed by one patient and do not necessarily reflect the feelings of the other subjects.

Goods of Character

Goods of character are personal moral perfections that include such virtues as temperance, justice, and fortitude. In this study, nine patients indicated that they were temperate. The tenth subject questioned whether or not he was temperate; he stated that the situation would determine his resistance to pleasure. Seven subjects provided some evidence of just behaviour on their part. All of the patients reported having fortitude. Many of the patients described considerable adversities that they had overcome. In many cases, the subjects also discussed other moral characteristics that they possessed, such as honesty and good temperment. Table 3 depicts each subject's possession or privation of the goods of character.

Temperance

Nine patients indicated that they possessed temperance, that is, that they thought that they were able to resist pleasure when it stood in the way of attaining other goods. Several patients stated that adhering to the dietary regimen was an example of temperance. However, most of the patients indicated that they occasionally "cheated" on their diet. For the most part, the subjects indicated that such episodes were uncommon; in the investigator's judgement, all

Table 3

Possession or Privation of Goods of Character

	Goods of Character			
Subject Number	Temperance	Justice	Fortitude	Other Moral Goods
1	X	X	X	
2	X		X	
3	X	X	X	
4	X	X	X	X
5	X		X	X
6	X		X	X
7	X	X	X	X
8	X	X	X	
9	X	X	X	X
10		X	X	

"X" indicates possession of the real good to the extent required to have a good life, as judged by the investigator in light of the Aristotelian-Thomistic philosophical theory of the good life.

No "X" indicates privation of the real good to the extent required to have a good life, as judged by the investigator in light of the Aristotelian-Thomistic philosophical theory of the good life.

but one on the patients possessed temperance to the extent required to have a good life. One man was uncertain about whether or not he possessed temperance. He admitted that the question that the interviewer asked of him about his temperance made him think about "all the things you know you shouldn't eat but you do eat sometimes".

Justice

Justice refers to acting fairly toward other people, respecting the rights of other people, and acting for the common good of the community. Although all of the subjects stated that they acted fairly toward others and several provided examples of their just behaviour, the statements of several patients seemed to indicate that they may not have truly possessed justice. For instance, when the subjects were asked to express their opinions about a current moral issue, that is, whether an individual should be allowed to purchase a kidney from a live, unrelated donor, two men thought it would be quite acceptable to purchase organs.

Fortitude

Fortitude refers to the moral strength or willpower to overcome adversities of all sorts and the courage to suffer pain for the sake of attaining other goods. When the patients were asked whether they would put up with pain or inconvenience to attain a good in the future, all of them responded affirmatively. Several indicated that undergoing dialysis treatment was evidence of fortitude. One man stated, "Yes ... I think I'm suffering enough". Another patient related that she had coped with many losses recently, including a number of deaths in her immediate family and her illness. She indicated that she had the courage to overcome her problems and to continue in her pursuit of other goals in life. In one case, a man described the things he did that the medical staff indicated that he would be unable to perform. He said that he "took it as a challenge" and was able to overcome the adversity, namely the limitations imposed by dialysis.

Other Moral Goods

Good temperment is a moral good that five of the subjects indicated that they possessed. One man stated that he had become better tempered since he started dialysis, because his outlook on life had changed. However, five patients reported that they were irritable, that is, they lacked good temperment. One man stated, "I am very irritable. I've always been short tempered but I have been able formerly to restrain my temper better than I can do now". One woman stated, "My nerves are not good. Everything irritates me". The patients reported that their irritability was a result of many things: fatigue, noisy grandchildren, difference of opinion with others, and anger regarding personal deficiencies.

The patients indicated that they possessed a number of other moral goods. All but one of them said that they were persistent. All of the subjects stated that they were "relatively" open-minded. Two patients reported that they were "honest to a fault". Two men stated that they were "perfectionists".

Goods of Personal Association

Goods of personal association refer to possessions in the form of a person's relationships with people, such as friends, family, and spouses. All of the subjects reported having close friendships and nine subjects reported that they had satisfactory family relationships. All of the six subjects who were married reported that they had good marital relationships. Table 4 depicts each patient's possession or privation of the goods of personal association.

Table 4

Possession of Privation of Goods of Personal Association

Subject Number	Friendship	Family Relationship	Marital Relationship
	Goods of Personal Association		
1	X	X	
2	X	X	X
3	X	X	
4	X	X	X
5	X	X	X
6	X	X	X
7	X	X	X
8	X	X	X
9	X	X	
10	X	X	

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No "X" indicates privation of the real good to the extent required to have a good life, as judged by the investigator in light of the Aristotelian-Thomistic philosophical theory of the good life.

Friendships

A friendship refers to a mutual caring relationship that exists between two people who are not related to each other and who act justly toward one another. All of the subjects reported that they had at least one close friend with whom they visited regularly and in whom they confided. All of the subjects stated that their friends were aware of their illness and treatment. One patient commented, "We haven't had any friends drop us because of my illness". She thought that the fact that her friends maintained their contacts with her indicated that they were true friends and that they cared about her. Most of the patients indicated that they received support and encouragement from their friends and that their friends were available to help them with other things as needed. Two patients stated that they did not require any emotional support from their friends (or others). One of these patients referred to his relationships with his friends as a "mutual appreciation admiration society".

Family Relationships

A family relationship refers to a relationship that exists between a person and his/her relatives. All of the patients possessed family relationships. Such relationships were of obvious importance to the subjects. One patient stated that he had siblings but that they did not see each other regularly: "I get along with them when I do see them. Neither one makes an effort". This man also had children whom he saw infrequently for a number of personal reasons. Some of the patients described the problems inherent in their family relationships. In general, the subjects reported receiving more help from their family members than from their friends. A daughter and a brother assisted with the dialysis treatments of two of the patients. Other types of assistance received by the patients from their family members included financial help, help with physical activities (such as mowing the lawn and housekeeping), and moral support. Three patients stated that a family member had offered them one of their kidneys for transplantation. In return, most of the patients reported that they would do whatever was necessary to help their family members.

Marital Relationship

A marital relationship refers to a type of friendship that exists between two people who have made a legal or verbal commitment to each other. It is usually characterized by a strong feeling of affection, devotion, and caring between the two people involved who would do whatever may be necessary to improve or enrich the life of the other person. All six of the subjects who were married reported that they had good marital relationships. Four spouses helped with the dialysis treatment.

Most of the subjects talked about their sexual functioning when questions about their relationships with other people were under discussion. One man reported that intimacy was more important to him now than the physical act of sexual intercourse. Another man stated, "I am not impotent but I have no desire anymore. If she expresses a desire, then we have sexual relations, but it has to come from her. It no longer comes from me, and it used to be the other way around".

Professional Relationships

Some of the patients described the relationships they had with their health care providers. Five of the patients reported that the hospital staff members were very supportive. One man, of higher social standing, indicated that he considered some of the physicians to be his friends.

Peer Relationships

With regard to their peer relationships, that is, the casual relationships they had with others in the community to whom they were not particularly close, three patients indicated that they had little or no contact with the other dialysis patients, by their own choice. Two patients reported that they had peer relationships with people they met through community work. None of the subjects had developed peer relationships with members of the Kidney Foundation, although many of them indicated some familiarity with the activities of the organization.

Social Goods

Social goods are those possessions that relate to human dignity, such as equality of opportunity, equality of treatment, and equality of status. Only four of the subjects indicated that they possessed equal opportunities for jobs. Eight subjects indicated that they possessed equality of treatment and equality of status. It is notable that many of the subjects identified that they received special treatment because of their illness. Table 5 depicts each patient's possession or privation of the social goods.

Equality of Opportunity

Equality of opportunity refers to the circumstance where people have the same or equal condition when beginning an activity. Four of the subjects indicated that they possessed equal opportunities with others for such things as jobs. However, the remaining six patients stated that they did not have equal opportunities for some jobs. One man stated, "You can tell on people's faces when they interview you. Right away - 'oh you've got kidney disease - sorry'". Another patient stated, "They say, 'Oh that's alright, we know you've got a problem but

Table 5

Possession or Privation of Social Goods

	Social Goods		
Subject Number	Equality of Opportunity	Equality of Treatment	Equality of Status
1		X	X
2	X		
3		X	X
4		X	X
5			
6		X	X
7	X	X	X
8		X	X
9	X	X	X
10	X	X	X

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that doesn't matter'. I think in the back it really does". One man talked about not having the same opportunity as a woman for a particular job for which he was applying.

Equality of Treatment

Of the 10 subjects, 8 indicated that they possessed equality of treatment, which refers to the circumstance where people are treated equally with respect to the fulfillment of their needs as human beings. Most of the subjects indicated that they even received special treatment because of their disease. One patient stated, "I tend to notice that they're a little bit more - maybe nicer". One man stated, "At one time ... I'd go to a party and the guys would say, 'Let's go into the kitchen and have a couple of shooters' ... Now they'll go but they won't ask me because they know I've got to watch my fluids and they know I don't drink like I used to". In another case, a woman commented that she was permitted to chew gum at work to alleviate her thirst, an activity which was prohibited for other employees.

One man indicated that he was not treated equally when he was in the hospital; he thought he had been treated like "a blob of meat". Another man indicated that he was treated like a "yo-yo" at work. The subjects who reported being treated equally made comments similar to the one made by a man who said, "I treat them as normal healthy people and they treat me as normal healthy people [sic] because I do not present myself as anything else". One man made an interesting point, when discussing his working conditions, which left something to be desired; he stated, "If you're going to be equal, you've got to be equal in the bad things as well as the good".

Equality of Status

Equality of status refers to the state where a person's standing or position in society is considered to be the same or equivalent to others in the sense of their humanness. This equality is closely linked to equality of treatment and opportunity. When the patients were asked about whether they were respected by others in the community, all but two of the subjects responded positively. The subjects who responded negatively were the ones who reported being treated differently from others. In some cases, the patients thought that they were respected more than other people because they were able to overcome adversities.

Political Goods

Political goods are those possessions that relate to government and governance of a person, such as political liberty, protection from harm, and freedom of action. Reports of 9 of the 10 patients indicated that they had political liberty, in that they had the freedom to participate in decisions that affected them. Many of them provided explicit examples of their involvement in making medically-related decisions. However, only two patients could state without qualification that they had freedom of action. Most thought that they were restricted by their condition, particularly in relation to travel. Seven patients indicated that they felt safe from harm. Table 6 depicts each patient's possession or privation of the political goods.

Political Liberty

Reports of 9 of the 10 subjects indicated that they possessed political liberty in the sense of freedom to participate in decisions, the outcomes of which affected them. All of the patients reported that they were consulted regarding major decisions in the home. In relation to dialysis, most of the patients made

Table 6

Possession or Privation of Political Goods

	Political Goods		
Subject Number	Political Liberty	Freedom of Action	Protection from Harm
1	X		X
2	X		X
3	X		
4	X		X
5	X		X
6			X
7	X		X
8	X		
9	X	X	X
10	X	X	

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No "X" indicates privation of the real good to the extent required to have a good life, as judged by the investigator in light of the Aristotelian-Thomistic philosophical theory of the good life.

comments similar to the following one: "I do it all basically, other than those things that are beyond my control ... I question it, I want to know about it, and I try to influence the decision, good or bad". One man stated in relation to the hospital staff, "I know enough that people won't get too intimidated if I ask questions. I think it's only right; that's my right as a person let alone ... patient". Another man referred to his freedom to make his own decisions by stating, "Whatever they [home dialysis staff] taught me I'm doing because that's what keeps me going, but I don't listen to everything they say to me ... You [referring to himself] know what you can do and you can't do ...". One man reported that he was permitted to select a specific brand of dialyzer and needles. Another man stated that he was surprised to find that the staff responded to his written concern relating to the safety of his machine: The staff performed an "experiment". The result was an upgrading of his existing equipment. In one case, a man spoke of how he was permitted to modify his dialysate composition when he dialyzed in an institution out of the country. The only man who indicated that he did not have political liberty, in the sense of participating in his care, had been involved in a dispute with the home dialysis staff. He thought that the staff did not understand his need for a specific aspect of his regimen which differed from that conventionally used by dialysis patients.

Freedom of A[illegible]

Only [illegible] of the subjects indicated that they possessed the liberty to act as they pleas[illegible] within the constraints of justice. Nearly all of the patients complained that they were not free to travel. One man stated, "I would love to be able to go to Hawaii when I want to and not have to wait until I'm accepted there [referring to receipt of notification that the dialysis unit in Hawaii could and would accommodate him], so I miss the freedom of movement very much".

Although a number of the patients had had some experience travelling since they had started dialysis, one man stated, "It's like captive moderation ... you be back in two days or you're going to feel rough". Another man stated, "Other people could [sic] be out running around doing things and I have to sit here, or other people can go on holidays at the drop of a hat and I have to make arrangements". The reports of four patients indicated that they were privated of freedom of action; they stated that their activities such as shopping, housecleaning, and playing volleyball were limited by their condition and the resultant lack of energy. The patients who indicated that they possessed freedom of action reported that they had become so accustomed to their routine that they no longer felt restricted. They seemed to possess enough freedom to have a good life.

Protection from Harm

Protection from harm refers to the state of a person's safety. Seven subjects indicated that they thought that they were safe from harm. One man stated, "Nobody would harm me. I've been harmed enough". Most of the patients indicated that they lived in safe neighborhoods. However, one man reported that he kept a large dog and a loaded gun in his bedroom to protect his property. Another man, who had been robbed twice, stated, "... what if they screwed up my machine". A woman expressed concern regarding her condition should she ever be kidnapped.

Economic Goods

Economic goods are those possessions or financial resources that a person needs in order to have a good life, such as free time, wealth, a means of subsistence, working and living conditions conducive to health, availability of medical services, and opportunities for self improvement. Of the 10 subjects, only

4 reported that they had enough free time to enjoy life. However, every subject, at some point during the interviews, expressed the desire for more free time or identified some activities that were limited by time. Nine of the subjects stated that they had enough wealth to enjoy life. Also, seven of the subjects indicated that they had a means of subsistence. All but two subjects indicated that their living conditions were conducive to health. In four cases, the reports of the subjects indicated that their working conditions were not conducive to health. For the most part, the subjects thought that necessary medical services were readily available. However, nearly all of the subjects had suggestions for improving the available health care services. All of the subjects indicated that they had opportunities for self-improvement, but many of them did not take advantage of these opportunities. Table 7 depicts each patient's possession or privation of the economic goods.

Free Time

Only four of the subjects indicated that they had enough free time, that is, time not devoted to work that can be used to improve oneself or society. It was interesting to note that three of these four subjects were not employed, possibly explaining the amount of free time available to them. However, even the patients who reported that they had sufficient free time made comments such as, "It seems like the machine takes up so much of your free time". The patients who were working indicated that they had little or no free time on the days that they dialyzed. As well, several patients reported that they did not have enough time to pursue activities such as taking more courses, visiting with friends, and spending time with family members. When asked if they had enough time to do nothing, if they so desired, most of the patients reported that dialysis was the time when they could sit and do nothing. The patients stated that they participated in a wide

Table 7

Possession or Privation of Economic Goods

	Economic Goods				
Subject Number	Free Time	Wealth	Working Conditions	Means of Subsistance	Living Conditions
1	X	X		X	X
2		X	X	X	X
3		X	N/A		X
4	X	X	N/A		X
5		X		X	
6	X		N/A		X
7		X	X	X	X
8	X	X	N/A	X	X
9		X		X	X
10		X		X	

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N/A refers to not applicable

Table 7

Possession or Privation of Economic Goods

	Economic Goods	
Subject Number	Availability of Health Services	Opportunity for Self-Improvement
1	X	X
2	X	X
3	X	X
4	X	X
5	X	X
6	X	X
7	X	X
8	X	X
9	X	X
10	X	X

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range of activities in their free time: reading, watching television, playing the guitar, dancing, target shooting, visiting with friends, gardening, skiing, golfing, and community work.

Wealth

Wealth is a financial or economic resource that results in prosperity and consists of such possessions as money, capital, and material belongings. All but one of the subjects reported that they had enough wealth to provide for their needs and to enjoy life. Seven patients stated that they owned their own homes, and several reported that they had other investments and resources. Three patients indicated that they were "well off". One man stated, "I can do anything I want ... my needs and my wants - I have all the money in the world for them". Another man, however, said, "Financially, too, it's been a little bit harder since I've been on the machine because I've changed jobs and took a lesser wage". However, this man reported that he had enough money to meet his needs. He desired more money to do things such as "finish" the basement. The man who reported that he did not have adequate financial resources to enjoy life stated, "We just manage - if we both had a job ...". He had been unable to find work. Although his wife worked, they incurred additional expenses as a result of the dialysis treatment. They needed a larger, more expensive apartment to accommodate the machine, and his medications cost them $50 a month. They could not afford to go out socially or to travel.

Means of Subsistence

Means of subsistence refers to the work done or the ways used to earn a living. Six of the subjects worked to earn a living; one man was a tradesman, one patient was a manager, two subjects were blue collar workers, one patient worked in retail sales, and one patient was a farmer. One man, who was retired, reported that he had "significant business interests". The remaining three subjects were not working; they indicated that they were provided with financial resources or a means of subsistence by their family members. Two of these patients thought that these resources were adequate. Hence, only one patient reported a privation of wealth.

Working Conditions Conducive to Health

Working conditions conducive to health refer to the circumstances related to health under which a person works. Of the six patients who were working, the reports of only two of the patients indicated that they possessed working conditions conducive to health. One man who possessed good working conditions stated, "My hours are fairly flexible ... if I want to leave during the day then I can". Another patient reported that her employer scheduled her work around her dialysis timetable. Three of the patients complained that their work environment was dry and dusty, contributing to their thirst. Two patients stated that they worked long hours, up to 14 hours a day on occasion. In one case, a man was concerned about the possibility of accidentally cutting his fistula at work; he reported that he frequently received cuts and nicks on the job. A farmer, who basically created his own working conditions, stated that he was exposed to a number of pesticides and herbicides.

Living Conditions Conducive to Health

Living conditions conducive to health refer to the circumstances conducive to health under which a person lives and travels. The reports of all but two of the subjects indicated that they possessed living conditions conducive to health. The two subjects who indicated that they did not possess this good reported that the dry, hot, summer climate made them thirsty; hence, they drank too much fluid and risked fluid overload. However, all of the patients reported that their housing was adequate. Many showed the investigator their dialysis rooms. Eight subjects reported that they owned and used cars as a means of transportation.

Opportunities for Self Improvement

All of the subjects reported that they had opportunities for self-improvement, that is, they had external resources available to them to assist them in the enhancement of their skill, knowledge, or character. Most stated that they could read or watch selected television programs to increase their knowledge. All were aware that courses were available, but seven subjects stated that they had no desire to participate in them. Three patients reported that they had, in the past, organized their schedules to take advantage of opportunities to increase their knowledge. In relation to their illness, all of the patients could identify opportunities to increase their knowledge. One man stated, "All you have to do is ask and you could get all kinds of information and books and stuff they [home dialysis staff] could suggest you read". All of the subjects indicated that they were aware of groups such as the Kidney Foundation and of classes in the hospital that were available for them. However, three patients stated that they were reluctant to participate in these classes. They indicated that many of the patients were not as healthy as they were and they did not want to spend their free time being reminded of their illness. Several patients also indicated that, although they possessed the opportunities to improve themselves, they lacked the time to take advantage of some of the available opportunities.

Availability of Health Services

Availability of health services refers to the existence of health services and ease of access to health care. All of the patients recognized the availability of dialysis treatment. Most of the patients expressed appreciation that the government provided them with a machine and supplies for dialyzing. One man stated, "If I had to buy the machine and pay for all this stuff, I think I would learn to steal". The support of nursing, technical, medical, and social services staff was acknowledged. However, all but two patients had suggestions for improving health services. One patient suggested that beds should be softer and more televisions should be purchased for the incenter dialysis unit; one person said that he would like medications to be provided without charge. Another patient thought that the government should pay the mortgages on the homes of dialysis patients. Yet another man thought that the government should purchase kidneys from living donors; he thought that this would save money in the long run. Difficulties with travel arrangements were of concern to two patients. One man stated, "I think ... dialysis facilities are very inadequate. The free movement of Canadians within Canada is very restricted and I think it is unfortunate and should be changed. There should be holiday dialysis centers away from hospitals, limited care centers ... It takes six months to get your money back from Medicare and if you've been away for four weeks and you pay $250 for [each] dialysis, it adds up to several thousand dollars which you have to pay out of your own pocket".

Possession or Privation of Instrumental Means to the Real Goods

Instrumental means refer to the actions performed by human beings or the set of circumstances that operate to bring about possession of the real goods. The patients possessed or were privated of five types of instrumental means:

physiological means, mental means, social means, economic means, and environmental means. Each type of instrumental means is presented in relation to the types of real goods to which it is related. Table 8 depicts the instrumental means which the patients possessed, and Table 9 depicts the instrumental means of which the patients were privated.

Physiological Means

Physiological means are those means that directly involve a person's bodily functioning or action upon a person's body or body parts. There are three major types of physiological means: nourishing activities, treatments, and state of health.

Nourishing Activities

Nourishing activities refer to those activities a person naturally carries out on a regular basis that serve to feed or sustain the body. They include: resting and sleeping, exercising, and eating and drinking.

Resting and Sleeping. The nourishing activities of resting and sleeping refer to the acts of relaxing, sleeping, and not moving. They were involved in the acquisition of goods of the body, goods of the mind, and goods of character. Eight of the subjects stated that they needed and received seven to eight hours of sleep per night. The other two patients reported that they only slept for four or six hours a night. Three patients reported that they took afternoon naps; three patients needed short rest periods during the day. With the exception of two patients, who received only four to six hours of sleep and were privated of an adequate amount of this means, the patients' reports indicated that they received adequate sleep and that rest and sleep resulted in their health and vigor. One man stated, "My whole well-being depends on how much sleep I get. If I don't get

TABLE 8

POSSESSION OF INSTRUMENTAL MEANS TO THE REAL GOODS

INSTRUMENTAL MEANS	REAL GOODS						
	GOODS OF THE BODY	GOODS OF THE MIND	GOODS OF CHARACTER	GOODS OF PERSONAL ASSOCIATION	SOCIAL GOODS	POLITICAL GOODS	ECONOMIC GOODS
Physiological							
Nourishing Activities							
Resting & Sleeping	X	X	X				
Exercising	X						
Eating & Drinking	X	X					
Treatment							
Prescribed							
Dialysis	X	X	X				
Medications	X						
Other Medical Treatments	X						
Non-Prescribed	X						
State of Health				X			
Mental							
Cognitive Strategies		X				X	
Attitudes and Approaches	X	X		X	X	X	X
Social							
Maintaining Contact		X	X	X			
Receiving Help	X	X	X	X	X	X	X
Giving Help				X			X
Economic							
Time							
Wealth							X
Work							X
Environmental	X						

"X" indicates that at least one subject possessed the instrumental means to the extent required to attain a real good, as judged by the investigator.

TABLE 9

PRIVATION OF INSTRUMENTAL MEANS TO THE REAL GOODS

INSTRUMENTAL MEANS	REAL GOODS						
	GOODS OF THE BODY	GOODS OF THE MIND	GOODS OF CHARACTER	GOODS OF PERSONAL ASSOCIATION	SOCIAL GOODS	POLITICAL GOODS	ECONOMIC GOODS
Physiological							
Nourishing Activities							
Resting & Sleeping	X	X					
Exercising							
Eating & Drinking							
Treatment							
Prescribed							
Dialysis							
Medications							
Other Medical Treatments							
Non-Prescribed							
State of Health	X	X	X	X	X	X	X
Mental							
Cognitive Strategies							
Attitudes and Approaches							
Social							
Maintaining Contact							
Receiving Help							
Giving Help							
Economic							
Time	X	X		X			X
Wealth				X			
Work							X
Environmental	X						

"X" indicates that at least one subject was privated of the instrumental means to the extent required to attain a real good, as judged by the investigator.

enough sleep, everything is a chore". Three subjects indicated that they rested to improve their health. Examples such as lying down to alleviate a headache were provided. In relation to vigor, several patients stated that they went to bed early, and other patients stated that weekends were used to catch up on sleep, so that they would have the energy to work during the following week. Three patients stated that they took short rest periods when they were performing activities, such as mowing the lawn, house cleaning, or shopping.

Resting and sleeping were also involved in the acquisition of goods of the mind. One man stated that "good rest and sleep" affected his feelings about dialysis and other things. He said that he was much more likely to feel positive about his situation when he was well rested. This man also indicated that he was less likely to become irritable if he had enough sleep. Therefore, sleep was also a means involved in the acquisition of goods of character. With regard to the two patients who indicated that they were privated of an adequate amount of these instrumental means, one of them reported that his ability to remember, to concentrate, and to judge were not as "sharp" when he lacked an adequate amount of sleep.

Exercising. Exercising, that is, the act of using the body's muscles or exerting the body, was involved in the attainment of goods of the body. Six patients stated that they participated in some form of exercise to maintain their health. Three patients stated that exercise helped them to prevent constipation and one patient reported that exercise promoted sleep. The reports of five patients indicated that they exercised to some extent to increase their vigor. Walking was the most commonly reported form of exercise in which the subjects participated. Some of the subjects reported that they occasionally played recreational football, did aerobic exercises, and did weight lifting. No patients indicated a privation of this instrumental means.

Eating and Drinking. All of the patients elaborated, in depth and with great detail, on their consumption of various types and quantities of food and fluid as a means involved in the acquisition of goods of the body. As well, some patients discussed diet as a means to goods of the mind. Three of the subjects reported that they did not need to follow any specific dietary regimen and they elaborated on their specific laboratory values that warranted individualization of their diets. However, the majority of the patients stated, "I feel better when I eat what I'm supposed to". Two patients reported that they restricted their intake of fats and cholesterol; these restrictions were not suggested by a physician. The patients undertook them because they thought that they would benefit from such a regimen. Several patients reported that they avoided foods high in potassium to prevent cardiac arrhythmias and foods high in sodium and fluid to prevent fluid overload. The patients reported that they tried to prevent constipation by eating bran, and raw fruits and vegetables, and by drinking coffee, prune juice, and adequate amounts of fluid.

All but two of the subjects reported that they restricted their fluid intake to prevent fluid overload. The actual volume of fluid consumed by the patients, as reported by them, ranged from 600 ml to 3 L a day. Two patients reported that they had no need to restrict their fluid intake since they were able to eliminate sufficient quantities of fluid. Six patients reported that they no longer consumed alcoholic beverages. Two of these subjects indicated that they had developed a distaste for alcohol since starting dialysis. These subjects thought that their non-consumption of alcoholic beverages was contributing to the enhancement of their health. In contrast, another man thought that drinking beer helped to increase his urine output.

Eating and drinking were also means involved in the acquisition of goods of the mind. One man indicated that his mental abilities were better when he "watched" his diet. Another subject thought that alcohol and coffee decreased his mental abilities so he generally tried to avoid these beverages. Similarly, another patient indicated that his good eating habits helped him to maintain his pleasurable feelings about his illness and his life.

Several patients indicated that they did not always use the instrumental means, "eating and drinking" appropriately. An unmarried patient ate very poorly; he consumed mostly bologna sandwiches and "fast foods". Most of the patients reported that, at times, they did not comply with their dietary regimens. For instance, one woman stated, "I kind of cheat once in a while and go have a hamburger and chips, or a pizza - but not very often". She thought that this noncompliance could contribute to her loss of health if continued to the extreme. Two patients drank heavily; they consumed at least three drinks every night and, on weekends, the quantity increased. One man indicated that drinking alcohol privated him of health; he felt ill when he drank. Another man noted that he developed a decrease in vigor when he drank too much fluid.

In one case, a man indicated that his prescribed diet limited his freedom of action. He thought that his diet prohibited him from eating what he wanted to when he went out. His need for a special diet kept him from visiting friends and from travelling since he worried about not being able to obtain the right foods, and the complications that might ensue if he deviated from his diet.

Treatments

Treatments refer to the prescribed and non-prescribed technical or artificial means a person uses to augment the nourishing activities. They consist of prescribed treatments, such as dialysis treatment and medications, and non-prescribed treatments.

Prescribed Treatments. Prescribed treatments are those remedies that are suggested or ordered by a health professional. One of the prescribed treatments, namely dialysis treatment, which involves the extracorporeal removal of excess fluid, electrolytes, and nitrogeneous wastes from the blood of a person with end stage renal disease, was a reported instrumental means to the attainment of goods of the body, goods of the mind, goods of character, and goods of personal association. However, several patients indicated that their dialysis treatments also interfered with the attainment of goods of the body, goods of the mind, goods of character, goods of personal association, political goods, and economic goods.

Two patients indicated that dialysis was a means to goods of the body. They reported that they ~~felt~~ unwell or "toxic" if more than two days elapsed between their treatments. One man indicated that dialysis contributed to his pleasures of sense. He reported that he dialyzed more frequently than other patients so that he could consume a more liberal diet and this increased the pleasure he received through the sense of taste. This man also believed that dialysis helped to increase the acuity of his senses.

The patients indicated that dialysis treatment was a means to goods of the mind. Two patients reported that, if they were not well dialyzed, their mental abilities, such as their ability to communicate, were not as good. They, therefore, made efforts to ensure that they dialyzed adequately. Two patients indicated that dialyzing well helped them to maintain positive or pleasurable feelings about various things.

One patient referred to dialysis as a means to goods of character. He stated that he dialyzed regularly to prevent the irritability that developed if he was "toxic" or not well dialyzed. Two patients indicated that dialysis was a means to goods of personal association since it brought them closer to a spouse or a friend. These patients viewed dialysis as a time when they could sit and talk.

Although dialysis, in fact, is generally viewed as a means to health and vitality for any person with renal failure, most of these patients indicated that it contributed to a privation of several goods. They associated dialysis with adverse symptoms, such as headaches, muscle cramps, nausea, poor coordination, and a decrease in general awareness. Two patients also stated that the machine "wears me out". They were referring to the fatigue or lack of energy that is prevalent postdialysis. One man reported that dialysis impaired his sexual functioning for approximately 10 hours after the treatment.

Three patients stated that, after dialysis, they had more difficulty concentrating and they did not feel as alert. Another patient reported irritability after dialysis as a result of the biochemical changes that occurred during the treatment.

In relation to the goods of personal association, one man reported that dialysis interfered with his family relationships. Dialysis kept him from visiting his father, and limited their visits to weekends.

Five subjects indicated that dialysis privated them, to some extent, of a political good, namely freedom of action. These patients stated that the time involved in dialyzing and the feelings of "unwellness" after dialysis kept them from doing some things that they wanted or needed to do, such as traveling, or shopping.

Several patients indicated that dialysis also contributed to a degree of privation of economic goods, such as free time and a means of subsistence. These patients stated that, if their dialysis time were reduced, they would have more free time. One patient reported that he was currently unable to work because his dialysis schedule prohibited him from accepting shift work.

Medications are chemical or biological substances that are prescribed by a licensed physician for the prevention, treatment, or cure of a disease. The subjects indicated that medications were means that were involved in the acquisition of goods of the body. In relation to these goods, several patients reported that some medications contributed to the improvement of their health. For instance, they said that the stool softeners and laxatives alleviated their constipation, calcium carbonate reduced their serum phosphate levels, and the steroids and a muscle relaxant alleviated other symptoms. One patient reported that an anabolic steroid increased his vigor by increasing his muscle mass.

Several patients also indicated that their medications also privated them, to some extent, of goods of the body, goods of the mind, and goods of character. Three patients indicated that a phosphate binder, aluminum hydroxide, and an "iron pill" contributed to a privation of health by causing constipation. Two patients indicated that a medication, aluminum hydroxide, contributed to a privation of goods of the mind; they thought it caused forgetfulness. One subject indicated that aluminum hydroxide contributed to a privation of goods of character by causing irritability.

Several patients indicated that they used other medical treatments as means to the acquisition of goods of the body. These were methods of managing symptoms, preventing disease, or promoting health, other than by dialysis or the administration of drugs, prescribed by a health professional. For instance, one patient stated that she used ultraviolet light to alleviate a rash and itching. Another patient stated that visiting the physician was one means he used to attain health. Three patients reported that they received regular blood transfusions to maintain their vigor. Two patients indicated that corrective lenses were, for them, means to both health and pleasures of sense. None of the subjects indicated a privation of these instrumental means.

Non-Prescribed Treatments. The patients' reports seemed to indicate that non-prescribed treatments, that is, remedies that a person initiates without the advice of a physician, were involved in the acquisition of goods of the body, goods of the mind, and economic goods. These treatments included a number of home remedies and smoking.

Several patients indicated that they used non-prescribed treatments to acquire goods of the body. They used various oils, lotions, and conditioners to treat their dry skin and hair. Two subjects reported that they chewed gum to reduce their thirst and to minimize their fluid intake.

Three subjects indicated that smoking, a non-prescribed treatment, reduced the acuity of their senses of taste and smell and reduced the sensual pleasures they acquired through these senses. One man indicated that cigarette smoking decreased his mental abilities.

State of Health

State of health or condition of the body or body parts was a circumstance that operated in the attainment of goods of personal association. One subject indicated that his state of health was involved in the acquisition of goods of personal association. This man stated that he had become more supportive of his wife since he had developed renal failure.

Generally, the reports of the patients indicated that they were privated of the instrumental means, state of health, in that their current health was not adequate for the attainment of real goods, and the ultimate good, the good life. In relation to goods of the body, several patients indicated that their symptoms of end stage renal disease contributed to a privation of health. For instance, several patients reported that their sexual dysfunctions were a result of their renal disease. Sinusitis decreased the acuity of one patient's sense of smell and, therefore, his pleasures of sense. Four patients indicated that their anemia (associated with renal failure) caused a privation of vigor.

The reports of several patients also indicated that they were privated of goods of the mind because of the state of their health. One man reported that his ability to remember was diminishing as a result of the normal aging process. Two patients indicated that the state of uremia (or being "toxic") impaired their ability to remember. One person reported that it impaired his ability to concentrate. Yet another man indicated that he had lost faith in God as a result of his state of health. Two subjects reported that their state of health caused irritability or a lack of good temperment.

Several patients indicated that the instrumental means, state of health, was not available to them. One woman indicated that her present state of health privated her of goods of personal association; she did not feel able to participate in social activities that helped to maintain her relationships with others.

Four patients indicated that their state of health privated them of freedom of action, a political good. Their current state of health prevented them from undertaking a variety of activities ranging from shoveling snow to working in developing countries.

Although several patients indicated a privation of social goods, only two patients directly attributed this privation to their state of health. These two patients believed that their job opportunities were limited by virtue of their illness. One man was forced to take a lower paying job as a result of his illness. He thought that this decreased the respect he received from others.

The reports of several patients also revealed that their state of health privated them of economic goods. One patient reported that he did not have the energy to maintain his living conditions through regular housekeeping activities. One man stated that if he were healthier, he would be able to work for a living.

Mental Means

Mental means refer to those means that involve a person's mind or intellect and will. These means encompass the cognitive strategies used by a person, and a person's attitudes and approaches.

Cognitive Strategies

Cognitive strategies are methods used by a person to obtain information or facts and to come to know and understand them. The common cognitive strategies that were used by the patients included reading, inquiring, observing, and reflecting.

The patients used cognitive strategies to acquire goods of the mind and political goods. In relation to the acquisition of goods of the mind, all of the subjects reported that they read to increase their knowledge and understanding of not only their illness but also of many other life situations. The patients read everything from newspapers and magazines to medical encyclopediae and medical journals. One patient stated that she read a brochure about sexual dysfunction in renal disease to increase her knowledge and understanding of this problem. Another man stated that he read some studies about the relationship between aluminum and brain disorders. Two patients reported that reading helped them to improve their mental abilities. Also, one man indicated that reading about the physical and psychological aspects of dialysis helped him to reconsider how he felt about his disease and its treatment. Two patients indicated that they used observation as a means to knowledge and understanding. In particular, one man reported that he learned about dialysis by sitting and listening to the other patients in the waiting room as they talked about their disorder.

Four patients stated that they talked to other people and asked questions to increase their knowledge. One man stated that he liked to talk to "professionals" to increase his knowledge about his disease. The other three patients indicated that they would ask questions "of people that know" about things they wanted to understand. Other cognitive strategies were also used. One man stated that he tried to improve his memory through the use of mental exercises. He mentally reviewed and tried to remember the day's events. Three patients reported that they watched television to increase their knowledge; they reported watching news programs and documentaries. One man indicated that he used cognitive means to acquire political goods. He spent time reviewing his chart and laboratory results to maintain his political liberty, in the sense of involvement in decisions that affect him.

None of the patients' reports indicated a privation of the instrumental means, cognitive strategies.

Attitudes and Approaches

A person's attitudes and approaches (that is his/her relatively enduring feelings, beliefs, or behavioral tendencies toward people, groups, objects, or ideas) were involved in the acquisition of nearly every type of real good. The patients' reports seemed to indicate that these means were important in the attainment of the goods.

Five patients used attitudes and approaches as means to the attainment of health. They stated that they tried to "live life to the fullest", to "stay active and in control of life", and "to maintain your previous workload and lifestyle". They indicated that these attitudes and approaches helped them to maintain their health and vigor. Two patients indicated that their attitude of being appreciative of things around them helped them to attain pleasures of sense.

In relation to the acquisition of goods of the mind, one man stated that he used an aggressive approach to gain knowledge about kidney disease and other things. Most patients reported that they needed a "good attitude" to maintain their pleasurable feelings. Two patients identified that they tried not to feel sorry for themselves. Two other subjects reported that they tried to be positive, accept the situation, and cope as well as they could. All of the patients said that their positive attitudes about their condition and its treatment helped them to maintain their positive feelings about their lives. One man stated, "If you accept it positively, you'll do better. If you don't, you get problems". Another man stated, "I look at each day ... and dialysis comes second. I don't think about dialysis. You have to do it, yes, but I really don't dread doing it. I really don't give it a lot of thought ... I can't dwell on it because I know it would get me down". Another man expressed a similar attitude when he said, "I feel it's like when you play poker. If you have a good hand, you play it, and if you've got a bad hand you got to play it anyway, so just play it and shut up [sic]. You're not going to get a better hand". One man stated that looking at situations with a sense of humor helped him to maintain some of his pleasurable feelings. He found that he felt better about his situation if he could laugh about it. Another man maintained his positive feelings by looking at things "day by day".

Many patients also indicated that their attitudes and approaches were involved in the acquisition of goods of personal association. Two patients tried to avoid placing unnecessary burdens on their family members or friends in order to maintain their relationships. Another three patients stated that they avoided complaining and feeling sorry for themselves in order to maintain their relationships.

Attitudes and approaches were also involved as means to the acquisition of social goods. Several patients reported that their positive attitudes about their illness gained them respect from others. Again, two men indicated that, by not complaining and "feel[ing] sorry" for themselves, they influenced the treatment they received from others. One man reported that his attitude was that he was "normal" and that he expected to be treated "as normal". Another man reported that he gave his "best effort" to everything. The patients thought that these approaches helped to ensure that they got the same opportunities as others for things like jobs.

A few patients indicated that their attitudes and approaches were means to the acquisition of political goods. Two patients indicated that their attitude of wanting to be involved in their care helped to increase their political liberty in the sense of involvement in decisions that affect them. Several patients also described approaches they used to maintain their safety. They avoided walking alone at night, they locked their doors at night, and they avoided leaving valuable items in accessible places.

One man indicated that his attitude of "do[ing] the best job I know how" contributed to the acquisition of economic goods. This acquisition helped him to maintain his means of subsistence.

At no time, did the subjects indicate a privation of the instrumental means, attitudes and approaches.

Social Means

Social means, that is, means that involve or arise from interaction between persons, were involved in the acquisition of several types of real goods. There are three categories of social means: maintaining contact, receiving help, and giving help.

Maintaining Contact

Maintaining contact refers to a person's attempt to continue to interact or communicate with people for purposes other than help; it was an instrumental means involved in the acquisition of goods of the mind, goods of character, and goods of personal association. In relation to the goods of the mind, two subjects reported that maintaining contact with knowledgeable people helped them to increase their knowledge. Another man indicated that his contacts with others served to maintain his mental abilities and to increase his pleasurable feelings about dialysis and life in general.

One man indicated that maintaining contact with certain people helped him to acquire goods of character. He thought that people influenced him and had an impact on his moral character.

Several patients indicated that their maintenance of contact was involved in the acquisition of goods of personal association. Most of the subjects indicated that it was important to communicate regularly with family members and friends to maintain or improve their relationships. The subjects reported that they spent time with their children, called their friends or family members on the telephone, and remained involved in the activities of their friends and family.

None of the patients indicated a privation of the instrumental means, maintaining contact.

Receiving Help

Receiving help refers to a person's receipt of assistance from others in the form of support, encouragement, services, or resources. These instrumental means were involved in the acquisition of each type of real good. In relation to the goods of the body, two patients reported that they received help with their dialysis from another person; they thought that this helped them attain a higher level of health. One man indicated that he received help in attaining goods of the body from his wife when she ate the same diet that he was required to eat. He also indicated that he received help with managing his dietary restrictions from other people who cooked special meals for him, taking into consideration his dietary restrictions. He believed that this helped him to maintain his health. One man reported that he received help with respect to ensuring his personal safety from friends who called him while he dialyzed to ensure that he was "alright". He considered this to be relevant to his health since he dialyzed alone without the assistance of a helper.

Receiving help was also a means involved in the acquisition of goods of the mind, specifically, pleasurable feelings. Many of the patients indicated that the support they received with respect to their emotional adjustment to dialysis from their family members and hospital staff helped them to maintain their pleasurable feelings.

The help that one patient received was a means involved in the acquisition of goods of character. She stated that her family and friends often "give me the courage to do things"; that is, they helped her acquire fortitude.

The patients indicated that receiving help from others contributed to the acquisition of goods of personal association. The subjects stated that they received help in the way of money, services, or support and encouragement from others. They thought that receiving help (and giving help) was necessary for them to maintain their friendships and family relationships.

The help that the patients received, from various organizations which increased public awareness about kidney disease, assisted in the acquisition of social goods. Two patients indicated that organizations such as the Kidney Foundation and the Human Rights Commission contributed to their attainment of equality of opportunity, equality of treatment, and equality of status by increasing the awareness of the general public about the plight of patients with renal disease.

Several patients indicated that the help they received from other people facilitated their acquisition of political goods. Four patients indicated that they received help in the attainment of political liberty from their nurses and physicians who encouraged them to participate in their care. One man stated that it helped him to receive a "push from the nurses" to begin home dialysis. The patients indicated that friends and family were also helpful in the acquisition of political liberty; specifically, some patients reported that a family member, spouse, or friend often encouraged them to become involved in activities in which they might not have otherwise participated. These activities facilitated their involvement in decisions, the outcomes of which affected them. In relation to protection from harm, two patients indicated that they received help from others; neighbors watched their homes while they were away.

Receiving help from others was also a means to the acquisition of economic goods. The patients stated that they received help from other people with activities such as setting up the dialysis machine and mowing the lawn; this left them with more free time. One man indicated that he received help with carpentry and maintenance of his house and that this contributed to the acquisition of living conditions conducive to health. Two patients stated that they received help with their housekeeping activities. As well, several subjects mentioned that they received help from the Kidney Foundation in the form of certain health services, such as the mobile dialysis unit.

None of the patients indicated a privation of the instrumental means, receiving help.

Giving Help

The provision of help, that is the offer or provision of assistance to other people in the form of support, encouragement, services, or resources, was involved in the acquisition of goods of personal association and economic goods. In relation to the goods of personal association, the patients indicated that they gave help to others as a means to the acquisition of or maintenance of goods of personal association. The subjects reported that they provided help to others in the form of babysitting, housework, physical labor, reassurance, and business related activities. Several of the subjects indicated that a mutual exchange of help was an important means to the acquisition of goods of personal association.

Three patients indicated that the giving of help to others was a means involved in the acquisition of one economic good, availability of health services. These patients stated that they helped with various Kidney Foundation fund-raising activities. These activities then contributed to the availability of a number of patient services through the Kidney Foundation.

None of the patients indicated a privation of the social instrumental means, giving help.

Economic Means

Economic means refer to those means that are financial in nature. They include wealth, work, and time.

Wealth

Wealth (referring to money, property, and possessions) was involved as an instrumental means to economic goods. One patient indicated that he used his wealth to acquire an economic good, that is, living conditions conducive to health. This wealth was necessary because he required a larger apartment to accommodate his dialysis machine. This cost him an extra $100 monthly.

One patient indicated a privation of the instrumental means, wealth, in relation to the goods of personal association. He reported that he required greater wealth so that he could visit family members, who lived out of the city, with greater regularity.

Work

Work, that is, labor performed by a person for remuneration, was a means to the acquisition of economic goods. One man indicated that his work was a means involved in the acquisition of health care services. He thought that his employment and that of other patients demonstrated the effectiveness of the dialysis treatment to government officials and that this demonstration would ensure continuing support for dialysis programs.

In relation to the goods of the body, two patients reported that their work caused fatigue and lack of vigor. Another man reported that, as a result of the nature of his work, he sustained many nicks and cuts to his hands. The reports of one man indicated that the nature of his work contributed to a privation of social goods. In the work situation, he was treated as a "yo-yo"; he thought a better job would increase the respect he received from others. The three patients who were not employed did not specifically discuss their privation of the instrumental means, work. However, it was obvious that they were privated of these means to wealth.

Time

Time refers to a span of clock time available or used for tasks or activities. This was an instrumental means of which the patients reported that they were privated. In relation to the goods of the body, three patients reported that a lack of time prevented them from getting enough sleep and exercise, and from eating adequate meals. In addition, one of these patients indicated that he often did not have time to fully enjoy sensual pleasures. For instance, he often did not have time to listen to music. In relation to the goods of the mind, one man reported a lack of time to increase his knowledge and understanding. Also, he stated that he had no time to daydream or think. In relation to the goods of personal association, six patients reported a lack of time. The patients stated that, if they had more time, they would be able to associate with more family members and friends. One man mentioned that, if he had additional time, he could become involved in community organizations. One man indicated that he was privated of enough time to attain an economic good, namely living conditions conducive to health. He stated that he did not have the time to maintain his home satisfactorily.

Environmental Means

Several patients indicated that means of an environmental nature, that is, the physical conditions in which they lived and worked, privated them of some of the goods of the body. Two patients reported that the hot weather contributed to their excessive intake of fluids and, thus, to fluid overload. The dryness of the climate was another environmental condition that two patients reported contributed to the dryness of their skin and hair. Two subjects reported that the dust and dirt in their work environments contributed to the development of dry skin, hair, and mouth.

Order of Importance of the Real Goods

The subjects' ranking of the importance of each type of real good was determined using a card sort task at the end of the first interview. Six of the 10 subjects identified goods of personal association as the type of real good which was of most importance to them. When asked to explain the reasons for their responses, one man stated, "... my family is very important to me. That is the reason I am on the machine. If it wasn't for my family, I probably would not carry on with it ...". Three patients ranked goods of the body as being of highest importance. One of these patients indicated that he would not have ranked this type of real good as highly if his health had been normal. Only one individual ranked goods of the mind as of the highest import. However, goods of the mind were consistently ranked as one of the four most important types of real goods. One man stated, "If I had a choice between a rugged, healthy physique ... and intellectual competence, I wouldn't hesitate. I would take the sick body and take the good brain, ...".

For the most part, the extrinsic goods (political, social, and economic) were ranked lowest by the subjects in terms of the importance of them to them. Some reasons given for this ordering were: "I have no problem with ... equality of treatment ... that would be the last thing on my mind", "You worry more about your own life ...", "... considering that we live in a democratic country ...", and "... these things are all guaranteed ...". The subjects' ranking of the importance of each type of real good is outlined in Table 10.

Order of Proportion of Time Spent in the Attainment and Enjoyment of the Real Goods

The subjects' ranking of the amount of time spent in attaining and enjoying each type of real good was determined using a card sort task at the end of the first interview. The patients spent less time explaining reasons for these rankings than those relating to the importance of the types of real goods. However, four patients indicated that they ranked goods of personal association as consuming the most time because they were always interacting with someone. Three of the 10 patients said that they spent the most time in attaining and enjoying economic goods. This was because they spent a great deal of time at work. Although three patients spent the highest proportion of time in acquiring and enjoying goods of the body, another four patients ranked the proportion of time spent in attaining

Table 10

Rank Ordering of Importance of the Real Goods

Real Goods	Rank Ordering by Subject Number									
	1	2	3	4	5	6	7	8	9	10
Goods of the Body	6	5	3	3	1	1	6	2	1	4
Goods of the Mind	1	2	4	2	4	3	2	3	4	2
Goods of Character	4	4	2	4	4	2	3	4	5	3
Goods of Personal Association	2	1	1	1	5	6	1	1	2	1
Economic Goods	7	3	5	5	2	4	5	6	3	6
Social Goods	3	7	6	6	3	5	4	5	7	5
Political Goods	5	6	7	7	6	7	7	7	6	7

"1" indicates the highest possible rank and "7" indicates the lowest possible rank.

and enjoying these goods fourth or lower in the rankings. Several patients stated that they spent little time maintaining their health apart from their dialysis. Even dialysis time (considered as time devoted to the goods of the body) was used to attain other goods through such activities as reading and interacting with people. Again, political and social goods were ranked lowest. As one patient said: "... you can't do much about them ...". The subjects' ranking of the proportion of time spent in the attainment and enjoyment of each type of real good is outlined in Table 11.

Summary

According to the Aristotelian-Thomistic philosophical theory of the good life, all people must possess and enjoy all the real goods in the right order and proportion in order to have a good life. The subjects of this study reported that they had fairly good general health, in spite of their illness. Only two patients reported having good energy or vigor. Seven patients indicated that they possessed vitality and nine patients indicated that they enjoyed pleasures of sense. In relation to the goods of the mind, all the patients stated that they possessed fairly good knowledge and understanding about various things, five patients indicated that they had no serious privations of the mental abilities about which they were asked, four patients indicated that they had faith in a higher being, and five patients indicated that they possessed pleasurable feelings. With regard to the goods of character, most of the subjects indicated that they acted temperately, justly, and that they possessed fortitude. At least five of the patients indicated that they possessed at least one other moral good.

Essentially, all of the patients indicated that they possessed goods of personal association. In relation to the social goods, four patients suggested that they possessed equality of opportunity and eight patients indicated that they

Table 11

Rank Ordering of the Proportion of Time Spent in Attaining and Enjoying the Real Goods

Real Goods	Rank Ordering by Subject Number									
	1	2	3	4	5	6	7	8	9	10
Goods of the Body	5	5	3	2	1	1	7	1	4	5
Goods of the Mind	3	2	4	3	5	2	2	2	2	4
Goods of Character	2	4	2	4	3	3	4	5	5	2
Goods of Personal Association	6	1	1	1	2	4	1	3	3	3
Economic Goods	1	3	5	6	6	6	6	6	1	1
Social Goods	4	7	6	5	4	5	5	4	6	6
Political Goods	7	6	7	7	7	7	3	7	7	7

"1" indicates the highest possible rank and "7" indicates the lowest possible rank.

possessed equality of treatment and status. Nine of the subjects indicated that they possessed the political good, political liberty, in the sense of involvement in decisions that affect the person. Only two subjects indicated that they possessed satisfactory freedom of action and seven patients reported that they were protected from harm. In relation to the economic goods, four patients stated that they had enough free time, nine patients indicated that they possessed enough wealth to live well, and two of the six patients who were working indicated that their working conditions were conducive to health. Seven patients indicated that they possessed an independent means of subsistence. Eight patients indicated that their living conditions were conducive to health. All of the patients indicated that health care services were available to them, and that they had opportunities to improve themselves.

The patients indicated that a wide variety of means were involved in the acquisition of each type of real good. The instrumental means that were most commonly involved or used to attain nearly every type of real good were attitudes and approaches, and receiving help. The patients' reports seemed to indicate that they were also privated of instrumental means to some of the real goods. Specifically, they indicated privations of the following instrumental means: some of the physiological means (resting and sleeping, and state of health); economic means (time, wealth, and work); and environmental means. The patients' reports did not indicate a privation of mental or social means to the real goods.

In relation to the importance of the real goods, it was found that the patients ranked goods of personal association highest. Political, social, and economic goods were ranked lowest in importance.

In relation to the time spent in attaining and enjoying the real goods, it was found that the subjects spent the most time in attaining and enjoying goods of personal association. The subjects who worked indicated that they spent a large proportion of time acquiring economic goods. Political and social goods were ranked lowest in this regard.

V. DISCUSSION AND LIMITATIONS OF THE STUDY

Discussion of the Findings

The responses of the home hemodialysis patients in this study revealed that they were seriously privated of some real goods. Over half of the subjects indicated that they were privated, to some extent, of health, vigor, spirituality, pleasurable feelings, freedom of action, and free time. According to the Aristotelian-Thomistic philosophical theory of the good life, such privations may prevent the subjects from attaining the total good, that is, a good life, unless they are overcome and the patients are able to acquire these real goods later in their lives.

Although many of the subjects reported that their health was good or fairly good, none could be labelled as "healthy" by the study's definition of "functional and structural integrity". It has been noted by researchers, that posing broad questions about health and satisfaction generally elicits a positive response. More detailed questioning uncovers areas of concern and difficulty (Antonovsky, 1979, p. 35). This phenomenon seemed to operate in this group of subjects; they reported good health generally, but when they were asked about specific aspects of their health, such as mobility or sexual functioning, their responses revealed that they were suffering substantial degrees of privation of this real good. Also, since the patients were not provided with the investigator's definition of health when the question regarding their health was posed, it may be that they responded using another view of health. This suggests that their reports of good health may not have been indicative of their possession of the real good, health, as defined by the investigator.

The findings of the study relating to the goods of the body and goods of the mind are consistent with those reported in the literature. It has frequently been noted that patients with renal failure have impaired health and experience alterations in their elimination patterns, sexual functioning, and skin and hair condition. Similarly, it has been recognized that the anemia related to renal failure causes fatigue (i.e., lack of vigor), and that healing and growth may be impaired with renal failure (i.e., lack of vitality) (Gutch & Stoner, 1979). In relation to the goods of the mind, privations of some mental abilities, such as the abilities to concentrate and remember, have been recognized among patients with renal failure by other researchers (Jungers, Zingraff, Man, Drueke, & Tardieu, 1978). Several patients were able to link the ingestion of one of their medications, aluminum hydroxide, to deficits in their mental abilities. This problem has recently become an area of greater concern in nephrology (Alfrey, LeGendre, & Kaehny, 1976). It is possible that the patients' reports may be a reflection of their knowledge and understanding of this problem and of the increasing concern of nephrology nurses and physicians about the problem.

A great deal of data was obtained pertaining to the patients' feelings. The patients tended to focus on their negative feelings. Although some subjects expressed pleasurable feelings, more negative feelings such as anger, resentment, and fear, were reported by the subjects. It may be that this focusing by the patients on their negative rather than positive feelings is an indication that the patients were feeling overwhelmed by their privations. In any case, feelings such as fear of needles, anger with hospital staff, and resentment about restrictions have been frequently reported in the literature in relation to dialysis patients (Kaplan De-Nour & Czackes, 1976; Kaplan, De-Nour, Shaltiel, & Czackes, 1968; Levy, 1974). Although the patients did not report many pleasurable feelings, they indicated that they had adjusted to their illness and that their attitudes and approaches were instrumental in this regard. The attitudes described by the patients tended to reflect positive or pleasurable feelings. This finding suggests that the patients may have possessed more pleasurable feelings than they reported.

It is also of note that the patients spent more time talking about their feelings about the hospital staff than they did about their feelings in relation to their families or friends. However, it is doubtful whether this reflects the importance of these various people to the patients. It may be that they thought that the investigator was particularly interested in their relationships with the hospital staff (although no specific questions were asked with regard to these relationships) or that she could effect change in this area.

The patients' feelings related to the other patients were surprising. Some patients specifically avoided interaction with other dialysis patients because of their feelings of hostility or sadness towards them. It might be expected, on the basis of the literature, that these patients would form a peer resource group to help each other with regard to minimizing the stigma associated with the disease (Becker, 1981). It is difficult to explain why the patients had these feelings, but it was obvious that they had been distressed by seeing other patients who were not faring as well as they were.

Death and dying did not seem to be of great concern to the patients. They appeared to be aware of the possibility of death, but few expressed great concern about dying. This finding is consistent with the finding of Kravette (1978) but contrary to the findings of other researchers who found that the fear of death is commonly reported by dialysis patients (Anger, 1975; Dickerson, 1980).

Most of the patients' reports seemed to indicate that they possessed the goods of character. Patients with renal failure have many opportunities to develop their moral virtues. They are continually faced with challenges and adversities; they are frequently required to make decisions involving temperance, courage, and justice. Since the moral virtues are acquired through practice, it may be that the patients in this study were able to develop their moral virtues as a result of their attempts to deal with the challenges and difficulties that they described.

It was difficult to attempt to accurately assess the patients' possession of goods of character. The questions that were asked of the patients were general, and few in number. Although most of the patients reported that they possessed the moral goods, it is possible that they provided socially desirable rather than valid responses. A comprehensive assessment of the patients' possession of goods of character would require another study. However, the possession of these goods may be among the most difficult to study scientifically since it is likely that responses to questions about moral character are subject to a response bias. People may give socially desirable responses to questions relating to their character. Also, objective measures of goods of character are not, as yet, available to validate reports of possession of these goods.

It was obvious that personal relationships (i.e., goods of personal association) were very important to the subjects. Not only did the patients identify the importance of this type of real good in the card sort task but they also frequently mentioned their families and friends during the interviews and reported that the help they received from others was an important means to some of the real goods. These findings are congruent with the Aristotelian-Thomistic philosophical theory of the good life in that, in this theory, human beings are thought of as social beings and as interdependent; they aggregate for their common good. It would be impossible to attain the real goods without goods of personal association. In the literature it has been demonstrated that social support is associated with both physical and mental well-being of both dialysis patients and groups of people in normal populations (Dimond, 1974; Dimond & Jones, 1983; MacElveen, 1972; O'Brien, 1980).

The equality of treatment, status, and opportunity of people with renal failure has not received much attention in the professional literature. However, in this study, several patients reported that they thought that they were not treated equally or given equal opportunities because of their illness. Most of the patients thought that they received special treatment because of their illness. This does not suggest that these patients were privated of equality of treatment. Adler (1981) states that human beings are equal only with respect to their humanness; in all other respects (such as intelligence, health, talent, and virtue) they are unequal. It is quite appropriate that these patients were treated somewhat differently because of their illness. This special treatment may have helped them attain equal opportunities with others. The patients who were privated of equality of treatment were not treated as human beings. It is possible, although unlikely, that the problems that were described by these patients are unique to these subjects. Nevertheless, this area deserves greater attention and further study, especially in the case of people who are experiencing inequities because of their illness, since the social goods are necessary constituents of a good life.

In relation to the political goods, the patients suffered some privation of freedom of action. Generally, it appeared as though the illness may have limited the patients' freedom of action. If, in fact, the illness privated the patients of this political good, this would imply that the patients would also be privated of a means to other real goods and to a good life, unless something occurred to change the situation. However, it may be that the patients desired more freedom of action than is necessary to have a good life. Some of them wanted the freedom to travel wherever and whenever they desired. Such freedom is more than necessary to meet natural needs.

At times, in relation to both political and economic goods, it appeared as though some of the subjects were expecting the government to help them to meet their wants rather than their needs. For instance, one man stated that the health services were not adequate because provision was not made for him to travel as extensively as he would like. Another man thought that mortgages of patients with renal failure should be assumed by the government. These statements seem to indicate that the patients desired means above and beyond what human beings have a right to expect from a government. A good government should help people attain only the real goods that they cannot obtain by themselves or with the assistance of their families. A government cannot meet individual wants since the interests of individuals must be subordinated to the welfare of society as a whole (Adler, 1984).

In relation to the economic goods, it appeared as though the patients were most seriously privated of free time. Those patients who were working had a particular problem with the acquisition of this type of real good. It appears as though both dialysis and employment occupied so much of the patients' time that little free time remained to pursue other real goods. This is of major concern, since free time is required to pursue leisure activities, a means to the real goods that are high in the scale of goods (Adler 1984). The patients who were not employed outside the home reported fewer concerns about lack of free time. Although dialysis time was used to pursue goods of personal association and goods of the mind, it appeared as though some patients required time, other than dialysis time, to pursue such goods. In this particular group of patients, other economic goods, such as wealth, living conditions conducive to health, opportunities for self-improvement, and availability of health services, were not areas of great concern since, on the whole, they possessed these types of real goods.

From the available data pertaining to both the real goods and the instrumental means, it appeared as though the possession of some real goods was related to the possession of instrumental means of the same nature. For instance, the patients who possessed goods of personal association used social instrumental means, such as receiving help, on a frequent basis. The patients who were privated of health were privated of a physiological instrumental means (state of health). Also, the instrumental means that were most frequently involved in the acquisition of various types of real goods, that is, a mental means (attitudes and approaches) and a social means (receiving help), appeared to be related to the possession of goods of the mind and goods of personal association. Similarly, the instrumental means of which some of the patients seemed to be privated [i.e., some of the physiological means (rest and sleep, and state of health) and the economic means (wealth, work, and free time)] seemed to be related to the privation of goods of body and economic goods. All of this suggests that a privation of a real good results in a privation of the instrumental means that are similar in nature to the real good. Such a situation could lead to a vicious cycle of privations that could interfere with the attainment of a good life.

It would appear from the patients' reports that some of the physiological means (dialysis treatment, and medications) and one of the economic means (work) were adequate in that they resulted in the attainment of the proximate ends, the real goods being pursued. However, they seemed to be inadequate for the attainment of the ultimate end, a good life, since in the process of attaining the real goods being pursued, they contributed to a privation of other real goods. For instance, work was a means to wealth for most of the patients. However, some of the patients were exposed to health hazards as they worked. These hazards contributed to a privation of the patients' health; such a privation interferes with the attainment of a good life. It appeared as though the involvement of such instrumental means (i.e., means that were adequate for the attainment of a real good and inadequate for the attainment of a good life) was largely outside the control of the individual patient, that is, the patient had little control over such instrumental means as dialysis treatment and medications. It seems that better instrumental means are needed, that is, those that are adequate for both the attainment of the real goods and the attainment of the ultimate good, a good life.

It was also noted that the patients did not always make appropriate choices with respect to some of the instrumental means, that is eating, drinking, and smoking. For instance, at times, they chose to smoke or to consume foods which were not appropriate given their condition. This suggests that the patients, in these instances, did not exhibit the moral virtues, such as temperance, and prudence; that is, they did not always make the right choices. In the investigator's judgement, however, most of the patients possessed the goods of character, to the extent required to have a good life, in spite of the occasional inappropriate choices. It appears that these instrumental means were not adequate in terms of either attaining the proximate end, the real good in question, or the ultimate good, a good life. Rather, the means appeared to satisfy a proximate want or desire.

The results of the card sort task were reviewed in light of the Aristotelian-Thomistic philosophical theory of the good life. In terms of the order of importance of the real goods to them, the patients did not necessarily rank the goods of highest order as most important to them. Goods of personal association and goods of the body were perceived by the patients, for the most part, to be of most importance. It may be that these types of real goods were necessary to a greater extent for these patients as instrumental means to other real goods. The data seem to support this hypothesis in that the patients reported a privation of the instrumental means, state of health. They thought that their present state of health interfered with the acquisition of the real goods. Also, the social means, particularly that of receiving help, were used frequently in the attainment of nearly all types of real goods. In terms of the patients' ranking of the extrinsic goods, it appeared as though the patients were not overly concerned about the possession or privation of these goods. The patients indicated that they took these things for granted. This may be a reflection of their perception that we live in what Adler (1978, 1981) termed a "good society".

The findings with regard to the patients' perceptions of the order of importance of the goods are somewhat different from those of other researchers. Campbell, Converse, and Rodgers (1976b) found that health was most important to their subjects (representative of the general American population), followed by marriage, family, and government. Harwood (1976) also found that health was most important to his subjects, followed by employment, community, and public safety. In these studies using healthy populations, the subjects rated health higher in importance than the subjects in this study, who had a chronic illness. This may be explained by the hypothesis that people with chronic illnesses have different perceptions of what is important as compared to people who are healthy. However, further study is necessary before any conclusions can be drawn about this matter.

In relation to the order of proportion of time the patients spent in the attainment and enjoyment of the real goods, it is surprising that more patients did not report spending a greater amount of time in attaining and enjoying goods of the body. Several patients indicated that they spent very little time in attaining and enjoying these goods even though such things as dialysis treatment, sleeping, and eating were included in this category. It appeared as though the patients may not have always considered these activities in their rankings. In general, the patients reported spending more time in attaining and enjoying goods of personal association and goods of the mind. It may be that the time spent in attaining goods of the body is taken for granted, because activities such as sleeping and eating are such a natural part of daily life. Also, the use of mental abilities and interactions with other people can be viewed as continuous activities since people tend to think or use their mind for most of the waking day and people are frequently interacting with others.

In the attempt to measure the concurrent validity of the card sort task with regard to the proportion of time spent by the patients in attaining and enjoying the real goods, it was found that most of the subjects were unable to report, during the interviews, how much time they actually spent, on a daily basis, in attaining and enjoying each type of real good. The patients were able to report that they spent most of their time using their mind and character and interacting with other people but could not give a specific time period that they spent in attaining and enjoying each type of real good. It may be that the questions were not clear. In future studies, it may be necessary to use a different approach to validate the instrument. Perhaps it would be easier for people to indicate specific time frames that they spend in attaining and enjoying various activities that are associated with each type of real good.

The Aristotelian-Thomistic philosophical theory of the good life formed the basis for the theoretical framework of the study. Through the utilization of this comprehensive conceptualization of the dimensions and requirements for a good life, that is, a life of quality, a more holistic study of quality of life of these patients was conducted than has been reported previously. Considerable data were elicited regarding the patients' possession or privation of the various types of real goods and instrumental means. Once further studies are carried out on patients receiving dialysis treatment for renal failure using this theory and generalizable findings are obtained, nurses should have a better understanding of what they need to address in relation to such patients' possession or privation of the real goods. As well, they may then be better able to identify the nursing means that could be used to improve the quality of life of patients receiving dialysis treatment for renal failure.

Limitations of the Study

This study is limited in that it does not provide a precise assessment of the patients' possession or privation of the real goods and instrumental means. On the basis of the patients' responses to the questions asked of them, it is difficult to draw firm conclusions regarding their possession or privation of the real goods or instrumental means. For instance, one cannot precisely assess the patients' possession of moral character or goods of the mind on the basis of their responses to a few questions.

Another limitation of the study is that no questions were asked with regard to the patients' enjoyment of the real goods. Since enjoyment of the real goods is an integral part of happiness or a moral quality of life, it is important that a comprehensive study of experienced quality of life address this aspect of the good life.

A further limitation of the study is that no objective measures of quality of life were used to validate the findings. It is possible that a response bias may have operated so that the subjects provided socially desirable responses. However, several objective observations by the investigator helped to validate some of the subjects' reports. For example, on observation, the living conditions of the patients were adequate, as reported by the subjects. The patients' knowledge and understanding of dialysis appeared to be adequate on the basis of informed discussions with the patients and observations made related to the dialysis procedures that were conducted during some of the interviews. Although such observations seemed to substantiate some of the results, it would be desirable to validate all of the findings with suitable objective measures.

The study is also limited, in that the data reflect the patients' perceptions at only one point in time. This is a limitation because it is possible that the subjective mood of the patients at the time of the interviews affected the results. Since pleasurable feelings are a function of the transient, psychological state of a person and may vary from day to day, the patients' reports relating to feelings (and perhaps other real goods) may have been colored by the emotional state of the patients at the time of the interviews.

The results obtained related to the consistency reliability of the card sort tasks are limited because the subjects may have been able to recall their previous responses given that the time interval between the two administrations of the card sort task was only one to two weeks. Ideally, the time span elapsing between the two administrations should be one to two months to reduce the likelihood of recall. However, given the timing of the interviews, it was not convenient to conduct the card sort tasks at a later time.

The results of the card sort task with regard to the proportion of time spent in the attainment and enjoyment of the real goods are limited in that the structure of the task may have been confusing to the patients. By addressing both attainment and enjoyment in one card sort task, it is not clear whether the patients interpreted the task as referring to one or both aspects of the task.

A final limitation of the study is the fact that the sample consisted of a small number of home hemodialysis patients who were selected on a convenience basis and who seemed to be non-representative of the population under study: the patients were considered by the hospital staff to be medically stable, it appeared as though all of the patients had adjusted relatively well to their illness, and no patient had any serious economic difficulties. Thus, the results of this study, given the small, non-representative sample used, cannot be generalized to any other group of patients or to any other settings.

Summary

The Aristotelian-Thomistic philosophical theory of the good life provided a useful, comprehensive framework for the study of quality of life of 10 home hemodialysis patients. The results that were obtained were examined in light of the theory. Possible reasons for possession or privation of the real goods and of the instrumental means were discussed. The results of the study cannot be generalized because a small, non-representative sample was used; no objective measures were used to validate the results; a detailed, precise study of the patients' possession or privation of the real goods and of the instrumental means was not carried out; the retest to establish the consistency reliability of the card sort was not carried out after a six week interval; the structure of the card sort task related to the attainment and enjoyment of the real goods may have been confusing to the patients; and the patients were studied at only one point in time.

VI. SUMMARY, CONCLUSIONS, AND IMPLICATIONS FOR NURSING

Summary and Conclusions

The purpose of this study was to describe the reported quality of life of a selected group of home hemodialysis patients. The following research questions were answered: (a) What types of real goods (constitutive means) do selected home hemodialysis patients possess? (b) Of what types of real goods are the patients privated? (c) What instrumental means are involved in the acquisition of each type of real good? (d) Of what instrumental means are the patients privated? (e) What is the importance placed by the patients on each type of real good? (f) What is the proportion of time spent by the patients in attaining and enjoying each type of real good?

The Aristotelian-Thomistic philosophical theory of the good life as interpreted by Adler (1941, 1965, 1970, 1971, 1980, 1981, 1984, 1985) was selected as the basis for the framework of the study because it provides a comprehensive description of a good life, that is, a life of quality. This theory describes seven types of real goods that are necessary for the attainment of a good life: goods of the body, goods of the mind, goods of character, goods of personal association, social goods, political goods, and economic goods. For a person to have a good life, he/she must acquire and enjoy the real goods in the right order and proportion and make good choices in the selection of instrumental means for the acquisition of the real goods.

A series of semi-structured interviews involving 10 home hemodialysis patients were conducted. An interview guide was developed for use during the interviews. It was tested and modified to attain face and content validity. Also, the patients were encouraged to add relevant aspects of their experiences that were not addressed by the investigator. The patients were asked questions pertaining to each of the real goods and were asked to identify any means that were involved in the attainment of each type of real good. A card sort task was used to determine the order of importance to the patients of each type of real good and the proportion of time spent by the patients in the attainment and enjoyment of each type of real good. A series of cards containing descriptions of each type of real good were presented to the patients. They were first asked to place the cards in the order of importance, to them, of the types of real goods; then they were asked to place the cards in the order of the proportion of time they spent in attaining and enjoying each type of good. A high test - retest reliability was obtained for the card sort tasks when retesting occurred one to two weeks following the initial testing.

The data analysis consisted of a content analysis, in light of the Aristotelian-Thomistic philosophical theory of the good life, of the patients' responses to the questions posed by the investigator about their present life. Categories and subcategories relating to the patients' possession or privation of the real goods and of the instrumental means to the real goods were established. The patients' statements were segmented into analytic units according to the established unit of analysis and distributed over the established categories and subcategories of possession and privation of the real goods and instrumental means. Data from the card sort tasks were reviewed and the patients' rankings were analyzed using descriptive statistical tests.

The following conclusions were based on the investigator's interpretation of the patients' reports, in light of the Aristotelian-Thomistic philosophical theory of the good life, and a few observations made by the investigator. No patient seemed to possess full health in the sense of structural and functional integrity. Because of this privation, and because of the apparent privation of the real good, vigor, the patients seemed to be privated, to some extent, of goods of the body.

In relation to the goods of the mind, it seemed that only one of the patients possessed the goods of the mind (i.e., those that were discussed in the interviews). The other patients appeared to be privated, to some extent, of one or more goods of the mind such as spirituality, mental abilities, and pleasurable feelings. On the basis of their reports, it seemed that most of the subjects possessed the following goods of character: temperance, justice, and fortitude. However, not enough data were available to draw firm conclusions regarding possession of these goods.

On the basis of the reports, all of the subjects seemed to possess goods of personal association. In relation to the social goods, four patients appeared to possess equality of opportunity, status, and treatment. At least three of the patients seemed to suffer some privation of these goods as a result of the way other people treated them. Although most of the subjects seemed to possess political liberty (in the sense of participating in decisions the outcomes of which affected them) and protection from harm, eight patients seemed to be privated, to some extent, of the political good, freedom of action.

In relation to the economic goods, it appeared that only one subject possessed all of the economic goods about which he was asked. Six of the patients appeared to be privated to some extent, of free time. One patient seemed to be privated of wealth, two patients appeared to suffer some degree of privation of working conditions conducive to health, and three patients appeared to be privated of a means of subsistence in the way of work.

The major categories of instrumental means involved in the acquisition of the real goods were as follows: physiological, mental, social, economic, and environmental. The most common instrumental means to the attainment of the real goods that the patients possessed included a mental means (attitudes and approaches) and a social means (receiving help). The means of which at least one patient seemed to be privated included some of the physiological means (rest and sleep, and state of health); the economic means (wealth, work, and free time); and environmental means.

From the patients' reports, it seemed that some instrumental means that were adequate in that they were effective in the attainment of a real good were inadequate in terms of attaining a good life because they contributed to a privation of other real goods. Specifically, dialysis treatment, medications, and work, fell into this category of instrumental means.

In relation to the importance of the types of real goods to the patients, it appeared that goods of personal association were of greatest importance to the patients, and the external goods (social, political, and economic goods) were of least importance to the subjects. The patients did not necessarily spend the most time in attaining and enjoying the types of real goods that were of greatest importance to them. Generally, they seemed to spend the most time in attaining and enjoying goods of personal association and goods of the mind.

The results of this study cannot be generalized because a small, non-representative sample was used, no objective measures were used to validate the results, and a detailed, precise study of the patients' possession and privation of the real goods and instrumental means was not carried out. Also, the assessment of quality of life that was carried out is incomplete because a dimension of it, that is, enjoyment of the real goods, was only tangentially examined. As well, the study is limited by the fact that the retest to establish the consistency reliability of the card sort task was not carried out after a six week interval, the structure of the card sort task related to the attainment and enjoyment of the real goods may have been confusing to the patients, and the patients were studied at only one point in time.

Adler (1981) stated that "... pursuit of happiness can be seriously impaired or even defeated by the injuries I suffer if I am enslaved, if my health is maimed, if I am deprived of sufficient wealth, if I am kept in ignorance, and so on" (p. 242). From the data obtained in this study, it appears as though the subjects of this study were suffering serious privations of some types of real goods that may prevent them from attaining a good life. However, given the limitations of the study, definitive conclusions cannot be drawn regarding the quality of life of these patients.

Implications for Nursing

On the basis of the study findings, conclusions, and limitations, a number of implications for nursing practice and research can be postulated. Although it is impossible to generalize from the findings, it is important for nurses to understand that patients with renal failure on home hemodialysis may suffer serious privations of some types of real goods. As well, it should be recognized that these patients may also be privated of instrumental means to some of the real goods. Some of these privations may be related to the patients' illness and treatment. With further research resulting in a better understanding of the ways in which these patients may be privated of the real goods and instrumental means, nurses may be able to plan appropriate interventions to help improve the quality of life of such patients.

Numerous research questions arise from the results and limitations of this study. Because a small, non-representative sample was used, a larger, random sample of patients should be used to permit generalizability of the findings. It would also be important to conduct a longitudinal study, examining the patients' quality of life over time. This would ensure that the results reflect the quality of the patients' lives over a longer period of time (i.e., several years) rather than the quality of life at one point in time. This would minimize the risk that the subjective mood of the subject colored his/her responses at the time of the data collection. It would also be significant to compare the quality of life of patients receiving different types of treatments for renal failure to determine what type of treatment offers the best possible quality of life for these patients.

Further work is required on the questionnaire. Explicit questions about all of the real goods are needed to ensure a more complete study of quality of life. As well, questions related to the enjoyment of the real goods should be added to the instrument since enjoyment of the goods is an inherent aspect of quality of life as defined in this study. This aspect of quality of life was only tangentially examined in this study. Ideally, one should seek further validation of the questionnaire, if an appropriate concurrent measure becomes available.

Further validation of the card sort is required. For the card sort regarding the proportion of time spent in attaining and enjoying each type of real good, questions about the specific amount of time spent in attaining and enjoying various activities pertaining to each type of real good should be included. This would facilitate concurrent validation of the card sort. Furthermore, it would be advisable to conduct two card sort tasks, rather than one, to more clearly address both the time spent attaining the real goods and the time spent enjoying the real goods.

Questions pertaining to some types of real goods, such as social goods, have not received much attention in the past. It is important to explore these areas in greater depth. Since goods of personal association were ranked high in importance by the patients, and since they were frequently used as instrumental means to other types of real goods, it is important to examine more closely the ways in which goods of personal association contribute to a good life. Furthermore, it is important to study the relationships between the possession or privation of instrumental means and of the various types of real goods to clarify what actions could be taken to assist patients in the attainment and enjoyment of the real goods.

It is also important to study and compare the quality of life of patients who are receiving various forms of treatment for renal failure. If it can be demonstrated, using comprehensive and valid research instruments, that a specific treatment modality, such as renal transplantation or continuous ambulatory peritoneal dialysis, provides a better quality of life for the patients, efforts should be made to use the treatments that offer the best possible quality of life.

As previously suggested, it may be that patients with renal failure have different perceptions regarding aspects of quality of life than do healthy people (e.g. with regard to the importance of various types of real goods). A study comparing the quality of life of people in a normal healthy population with the quality of life of people with various chronic illness may clarify why and how people cope with chronic illnesses.

In spite of many limitations, this study is important, since a comprehensive conceptualization of quality of life was used. Few, if any, studies to date have examined the quality of life of a group of people using such a comprehensive approach. This study is also important in that it has identified that patients with renal failure on home hemodialysis may suffer privations of some real goods and instrumental means that could interfere with the attainment of a good life. However, numerous questions related to the quality of life of the patient with renal failure remain. Since this study raises more questions than it answers and since nurses require a greater understanding of the quality of life of patients with renal failure, it is vital that further research be conducted in this area.

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APPENDIX 1

THE REPORTED QUALITY OF LIFE OF SELECTED HOME HEMODIALYSIS PATIENTS

INTERVIEW GUIDE

I will be asking you a number of questions about various aspects of your life, particularly as they relate to your kidney problems. When I talk about kidney problems, I mean the disease, dialysis treatment, and any other treatments related to your disease, such as medications and diet. As we proceed, please add anything that you think is significant that I have not asked you about.

GOODS OF THE BODY

1a. What is the state of your health at present, that is, what is the physical condition of your body and how it functions?

Prompting questions: (to be asked only if appropriate to situation and previous responses)

- Are you able to move around as freely as you need to?
- Do you have any pain at any time? If so, would you describe it (e.g., where, how often, how long, how severe)?

1b. What, if anything, do you do to maintain or improve your health?

Prompting questions:

- Do you rest to maintain or improve your health?
- Do you smoke? If so, how much do you usually smoke?
- Do you drink any alcohol? If so, how much do you usually drink?

1c. Can you identify any factors that help to maintain or improve your health, or worsen it? If so, what are they?

1a. What are your diet and eating habits like?

Prompting questions:

- How much food do you usually eat?
- What types of food do you usually eat?
- In a day, how often do you usually eat?
- Are you gaining or losing weight? If so, is this gain or loss intentional?

2b. What, if anything, do you do to maintain or improve your health through your eating habits?

2c. Can you identify any factors which help to maintain or improve your diet and eating habits or worsen them? If so, what are they?

3a. What and how much fluid do you usually drink?

Prompting questions:

- When do you usually drink fluids?
- How much fluid do you usually drink?
- What type of fluid do you usually drink?
- Do you restrict your fluids in any way? If so, how?

3b. What, if anything, do you do to maintain or improve your fluid intake patterns?

3c. Can you identify any factors that help to maintain or improve your fluid intake patterns, or change them for the worse? If so, what are they?

4. What are your elimination patterns (e.g., urination, bowel, and sweating patterns) like?

Prompting questions:

- How much urine do you usually pass per day?
- In a day, how often do you pass urine?
- How often do you usually have bowel movements?
- Do you have any problem with constipation? If so, would you describe the problem?
- Do you have any problem with diarrhea? If so, would you describe the problem (e.g., how often, when, how severe)?
- Do you have any nausea or vomiting? If so, would you describe the problem (e.g., frequency, severity, duration)?
- How much would you say that you usually sweat (or perspire)?

4b. What, if anything, do you do to maintain or improve your elimination patterns?

4c. Can you identify any factors that help to maintain or improve your elimination patterns, or change them for the worse? If so, what are they?

5a. What are your sleeping patterns like?

Prompting questions:

- How much sleep do you usually get per day?
- When do you usually sleep (at what times of the day)?
- Do you think that you need more or less sleep? Why?

5b. What, if anything, do you do to maintain or improve your sleeping patterns?

5c. Can you identify any factors that help to maintain or improve your sleeping patterns, or change them for the worse? If so, what are they?

6a. How sharp are your senses (e.g., hearing, seeing, tasting, smelling, touching)?

Prompting questions:

- How well are you able to hear?
- How well are you able to see?
- How well are you able to taste?
- How well are you able to smell?
- How well are you able to feel things that you handle or touch?
- How aware are you of things around you?

6b. What, if anything, do you do to increase or maintain the sharpness of your senses?

6c. Can you identify any factors that help to maintain or improve the sharpness of your senses, or worsen it? If so, what are they?

7a. Have you noticed any irritability in yourself? If so, could you please describe what it is like?

Prompting questions:

- Do you find yourself getting irritated easily by:
    1. music?
    2. noise?
    3. others around you?
    4. anything else (e.g., lack of sleep, movement)?
- Do little things that happen around you usually annoy you (e.g., lack of courtesy, tardiness, traffic)?
- Do you consider yourself to be short-tempered?
- How often do you usually get upset (i.e., number of times per day)?

7b. If you are irritable, what, if anything, do you do to reduce your degree of irritability?

If you are not irritable, what, if anything, do you do to maintain or improve your state of non-irritability?

7c. Can you identify any factors that worsen your irritability? If so, what are they?

8a. What is your energy level like?

Prompting questions:

- Do you have the energy to work? If so, what type of work are you able to do?

- Do you have the energy to take care of yourself (e.g., bathe yourself, brush your teeth, and dress yourself)?
- What household activities (e.g., housework, carpentry, gardening, and cooking) do you have the energy to do?
- Do you have the energy to exercise? If so, what type of exercise do you usually do (e.g., sports, running, walking, and walking up and down stairs)? How often do you usually exercise? For how long?
- Would you describe your muscle strength?

8b. What, if anything, do you do to increase or maintain your energy level?

8c. Can you identify any factors that help to maintain or improve your energy level, or worsen it? If so, what are they?

9a. How would you describe your body's state of vitality, that is, the growth and condition of your hair, skin, nails, etc.?

Prompting questions:

- How would you describe the condition and growth of your hair?
- How would you describe the condition and growth of your nails?
- How would you describe the condition of your skin (e.g., moisture, texture, complexion, lesions)?
- Would you say that you usually heal slowly, quickly, or in about the same time as most people (e.g., with cuts, needle punctures, incisions)?
- Have you noticed any general deterioration of your body (e.g., weakness, debilitation)? If so, what have you noticed?

9b. What, if anything, do you do to improve or maintain the growth and condition of your:

1. hair?
2. nails?
3. skin?
4. other parts of your body?

9c. Can you identify any factors that help to maintain or improve the growth or condition of your hair, nails, skin, or other parts of your body, or worsen it? If so, what are they?

10a. Are you able to obtain pleasure through the senses of hearing, seeing, touching, tasting, and smelling? If so, in what way(s) do you obtain such pleasures?

Prompting questions:

- Do you listen to music? If so, do you get pleasure from listening to music?
- Do you get pleasure from the taste of food?
- Do you notice smells, such as from perfume, leaves, and food? If so, do you get pleasure from these smells?
- Do you take time to look at the scenery around you? Do you get pleasure from that?
- Do you derive pleasure from looking at other things? If so, what are they?
- Do you have physical contact with other people?
- Do you get pleasure from having physical contact (i.e., touch) with other people?

10b. What, if anything, do you do to maintain or increase the pleasure you get through your senses?

10c. Can you identify any factors that help to maintain or improve the pleasure you get through your senses, or decrease it? If so, what are they?

11. Typically, how much time in a 24 hour day do you spend (e.g., through washing, sleeping, eating, dialysis) on maintaining or improving your health, vigor, vitality, and getting pleasure through your senses?

GOODS OF THE MIND

12a. How would you describe your ability to:

1. remember?
2. think?
3. reason?
4. make judgements and decisions?
5. inquire, question, and wonder?
6. imagine?
7. concentrate?

- Do you daydream, hope, or fantasize about anything? If so, what?
- Do you engage in any creative activities? If so, what do you do?
- Do you spend any time thinking about the worth and purpose of life, or about life and death? If so, what do you think about with regard to these matters?

Prompting questions:

- What kind of things do you think about?
- How well do you think you are able to make decisions at work? Please explain.
- How well do you think you are able to make decisions at home? Please explain.
- How well do you think you are able to judge things?
- Would you describe how you usually approach a problem that you face?
- Would you say that you have "common sense"?
- Do you participate in any creative activities such as art, writing, crafts, designs, or woodwork? If so, what do you do?
- Are you able to learn new things readily? If not, why?
- Are you aware of your own strengths and weaknesses? If so, what are they?

12b. What, if anything do you do to maintain or improve your ability to:

1. remember?
2. think?
3. reason?
4. make judgements?
5. inquire?
6. imagine?
7. concentrate?
8. be creative?
9. contemplate?
10. hope and dream?

12c. Can you identify any factors that help to maintain or improve your mental abilities that we've talked about, or worsen them? If so, what are they?

13a. Would you describe your ability to communicate (e.g., through writing, and speaking, reading, and listening)?

Prompting questions:

- How well are you able to convey what you think and how you feel?
- How well are you able to understand what others say or understand the feelings they express?
- Do you have problems with people not understanding what you mean? If so, under what circumstances?

13b. What, if anything , do you do to maintain or improve your ability to communicate?

13c. Can you identify any factors that help to maintain or improve your ability to communicate, or worsen it? If so, what are they?

14a. How would you describe your general knowledge and understanding of life situations? By life situations, I mean situations or events that occur as we live out our lives, and that affect how we "live" (e.g., death of a family member, illness, poverty)?

Prompting questions:

I would like to ask you about some life situations that kidney patients may face.

- What do you think about someone advertising to purchase a kidney for transplantation?

- Do you think that organs should be automatically removed from a body upon death without consent of the family or individual?

14b. What, if anything, do you do to maintain or increase your general knowledge and understanding of life situations?

14c. Can you identify any factors that help to maintain or increase your general knowledge and understanding of life situations or worsen it? If so, what are they?

15a. How would you describe the spiritual aspect of your life (i.e., in terms of faith, religion, etc.)?

15b. What, if anything, do you do to maintain or improve the spiritual aspect of your life?

15c. Can you identify any factors that help to maintain or improve the spiritual aspect of your life, or worsen it? If so, what are they?

16a. Would you describe how you feel about your kidney problem? Is there anything or anyone you have strong feelings about? If so, what or whom?

Prompting questions:

- How do you feel about being on dialysis?
- Do you ever feel:
    1. angry?
    2. hurt?
    3. upset?

4. sad?

5. happy about your condition?

16b. What, if anything, do you do to alter or sustain how you feel about:

1. dialysis?

2. other things or people?

16c. Can you identify any factors that help to sustain or improve how you feel, or alter how you feel for the worse? If so, what types of things affect how you feel?

17. Typically, how much time in a 24 hour day do you spend thinking, making decisions, creating, inquiring, acquiring knowledge and understanding, etc.?

GOODS OF CHARACTER

18a. How would you describe your moral character, in terms of being just, tolerant, courageous (in the face of adverse circumstances); that is, what would you way about the strength of your character?

Prompting questions:

- Would you say that you are a patient person? If so, in what way?
- Do you get irritated easily with others? If so, under what circumstances? What do you do about your irritability?
- Would you say that you are open minded? If so, in what way?
- Would you say that you are persistent? If so, in what way?

- Would you typically choose to give up some time and pleasure for some future benefit? If so, under what circumstances would you do so?
- Would you typically choose to give up a favorite food that is not on your diet in order to maintain or improve your health, or prevent complications?
- Would you typically choose to suffer some inconvenience at the present time, for some future benefit such as improving your health or preventing complications? If so, when does this happen?
- Would you say that you are a fair or just person in terms of your dealings with others (e.g., family, friends, strangers)? If so, in what way?

18b. What, if anything, do you do to sustain or improve your moral character (i.e., your courage in the face of adverse circumstances, sacrificing pleasure or putting up with pain to attain a good end, giving another his due)?

18c. Can you identify any factors that improve or sustain your moral character, or weaken it? if so, what are they?

19. Typically, how much time in a 24 hour day, if any, do you spend sustaining or improving your moral character (e.g., making decisions about right and wrong, being just, courageous, etc.)?

GOODS OF PERSONAL ASSOCIATION

20a. How would you describe your family relationships?

Prompting questions:

- Typically, how often do you see your:
  1. parents?
  2. children?
  3. siblings?
  4. other relatives?
- How would you describe the relationship between you and your:
  1. parents?
  2. children?
  3. siblings?
  4. other relatives?
- Do your family members usually volunteer to help you with anything? If so, who usually helps you?
- What types of things do they help you with (e.g., assuming some of your responsibilities, supplying things, giving support and encouragement)?
- Do you usually get the help that you need from your family members? If so, from whom?
- Do you usually help your family members in any way? If so, whom do you help? What types of things do you do to help?
- Do you feel loved by your family? If not, why do you not feel loved?

20b. What if anything, do you do to maintain or improve your family relationships, or worsen them? If so, what are they?

20c. Can you identify any factors that maintain or improve your family relationships, or worsen them? If so, what are they?

21a. Would you describe your love relationship(s)?

Prompting questions:

- How does your spouse / boyfriend / girlfriend feel about your kidney problem?
- How would you describe the relationship between you and your spouse / boyfriend / girlfriend?
- Do you find yourself getting irritated easily by your spouse / boyfriend / girlfriend?
- Do you usually receive help from your spouse / boyfriend / girlfriend? If so, with what types of things does he / she help you (e.g., assuming some of your responsibilities, supplying things, giving support and encouragement)?
- Do you usually help your spouse / boyfriend / girlfriend in any way? If so, what types of things do you do for him / her?
- Does your kidney problem interfere in any way with your love relationship(s)? if so, in what way?

21b. What, if anything, do you do to expand, nourish, or maintain the love relationship(s) that you have?

21c. Can you identify any factors that help to maintain or improve your love relationship(s), or worsen them? If so, what are they?

22a. Would you describe your friendships?

Prompting questions:

- How many close friends do you have?
- How often do you usually see your friends?
- Who typically initiates the contact – you or your friend(s)?
- What is your relationship like with your friends?
- Do you find yourself getting irritated easily by your friends? if so, under what circumstances?
- Do your friends usually help you? If so, in what way?
- Do you usually give your friends any help? If so, in what way?
- Do you feel that your friends care about you? If not, why do you feel that they do not care about you?

22b. What, if anything, do you do to develop or maintain your friendships?

22c. Can you identify any factors that help to maintain and improve your friendships, or change them for the worse? If so, what are they?

23a. Are you involved in any fraternal or community organization(s) (e.g., Kidney Foundation, Lions, Kinsmen, Community League)? If so, in what organization(s) are you involved?

Could you describe the relationship you have with people in the organization(s)?

Prompting questions:

- Do you have any friends in the organization?
- Does anyone in the organization give you any help?
- If so, what kind of help do they give you?

- Do you help the organization or anyone in the organization? If so, how do you help?

23b. What, if anything, do you do to increase or maintain your involvement in the organization(s)?

23c. Can you identify any factors that help to improve or maintain your involvement with the organization(s), or reduce it? If so, what are they?

24a. How would you describe the respect you get from others?

Prompting questions:

- Are you treated differently than others in the community? If so, in what way?
- Do you believe that people think you are important or worthwhile as a person?
- Do people usually show you the respect that you think any person deserves? If so, how?
- Do you usually treat some people differently than others around you, with regard to respect, importance, etc.? If so, how?

24b. What do you do, if anything, to maintain or increase the respect you receive?

24c. Can you identify any factors that help to improve or maintain the respect you receive from others, or reduce it? If so, what are they?

25. Typically, in a 24 hour day, how much time do you spend maintaining or improving your relationships with others (friends, loves, family, associates)?

POLITICAL GOODS

26a. Do any government actions or regulations have any effect on the availability of treatment for your kidney disease? If so, what?

Prompting questions:

- What services or funds, that you know of, does the government (or social agencies) provide for patients with kidney disease?
- Are these services or funds adequate? If not, why are they inadequate?

26b. What is being done by you and others to ensure government support of renal failure programs?

26c. Can you identify any factors that help to maintain or increase government support of renal failure programs, or decrease it? If so, what are they?

27. Do you usually participate in decisions relating to your treatment or care? If so, how? If not, why do you not participate?

Prompting question:

- Do you discuss decisions about your care with your doctor or nurse? If not, why do you not discuss these decisions?
- Do you have input into decisions about your treatment or care? If not, why do you not have input?

- Is your consent obtained before a new treatment (medication, etc.) is started? If not, do you know why your consent is not sought?
- Is the atmosphere in the home dialysis unit conducive to your participation in your care? If not, why is the atmosphere not conducive to your participation?

27b. What is being done by you or others to ensure your participation in your care?

27c. Can you identify any factors that help to improve or maintain your participation in your care, or reduce it? If so, what are they?

28a. What is your role in terms of management of the family?

Prompting questions:

- Who would you say acts as head of the household in your home?
- Who usually makes major decisions about finances in your home?
- Who usually makes major decisions about discipline in your home?
- Are you consulted about major decisions that affect you or your family? If not, why do you think that you are not consulted?

28b. What is being done by you and others to help you manage your home and family?

28c. Can you identify any factors that help to improve or maintain your role in managing your home, or change it for the worse? If so, what are they?

29a. Do you have the freedom to pursue actions or activities you need to undertake? If not, why do you not have this freedom?

Prompting questions:

- Are you prohibited from doing things you need to carry out by your:

  1. condition?
  2. family?
  3. friends?
  4. other associates?
  5. treatment personnel?
  6. other people or things?

  Please specify.

  If so, in what way?

29b. What is being done by you or others to maintain or increase your freedom to pursue actions or activities?

29c. Can you identify any factors that help to increase or maintain your freedom to pursue actions or activities, or reduce it? If so, what are they?

30a. Do you consider yourself to be safe from personal harm? If not, why?

Prompting questions:

- Are you concerned about robberies, attacks, or violence in the community?
- Do you worry about someone or something harming you? Please explain.

30b. What is being done by you and others to maintain or increase your safety?

30c. Can you identify any factors that help to increase or maintain your safety, or reduce it? If so, what are they?

31. In a 24 hour day, how much time do you typically spend managing your home, participating in your care, ensuring your freedom to do what you need to do, engaging in political activity, or trying to influence things that affect you?

SOCIAL GOODS

32a. Are you treated equally with other people with regard to things that affect a person's dignity? If so, in what way? If not, how are you treated?

Prompting questions:

- Do you believe that you have the same opportunities for such things as jobs, positions, treatment, and care as anyone else?
- Does anyone treat you as though you were an object or an animal (that is, not a person)? If so, why do you think this happens?

32b. What is being done to ensure that you have equal opportunities with others, on any count?

32c. Can you identify any factors that help to maintain or improve your equality of opportunity for jobs, treatment, positions, or care, or reduce it? If so, what are they?

33. In a 24 hour day, how much time, if any, do you typically spend trying to ensure your equality of opportunity?

ECONOMIC GOODS

34a. Are your working conditions adequate (both at home and at work)?

Prompting questions:

- Would you describe your working conditions (e.g., physical environment, benefits)?
- Does your work situation present any problems with regard to your kidney problem? If so, what kind of problem?

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34b. What is being done by you and others to maintain or improve your working conditions?

34c. Can you identify any factors that help to maintain or improve your working conditions, or worsen them? If so, what are they?

35a. Are your living conditions adequate? If so, in what way are they adequate? If not, in what way are they inadequate?

Prompting questions:

- Could you describe your living conditions (e.g., housing, transportation)?
- Do your present living conditions (e.g., housing) present any difficulties for you with regard to your kidney problem? If so, what kind of difficulties?

35b. What is being done by you or others to maintain or improve your living conditions?

35c. Can you identify any factors that help to improve or maintain your living conditions, or worsen them? If so, what?

36a. Are your finances (e.g., wealth, poverty, and possessions) adequate to live comfortably and enjoy life? If not, in what way are they inadequate?

Prompting questions:

- Do you need to watch your budget closely? If so, why?
- Can you afford to:
    1. take courses?
    2. go to the theater?
    3. travel?
    4. pursue satisfaction of your needs?

36b. What is being done by you and others to maintain or improve your financial situation?

36c. Can you identify any factors that help to improve or maintain your financial situation, or worsen it?

37a. Do you have a way to make a living? If so, how do you earn a living? If not, why are you unable to earn a living?

Prompting questions:

- Do you have a steady job? What is it?

- Do you consider this to be a "good" job, that is a job that you enjoy, and that pays you enough to live comfortably?
- If you do not have a "good" job, are you getting the education or training you need to get such a job? Is this training available?
- Do you have the money or capital (e.g., machinery, tools, money for investments) to earn a living if you are not working for someone else?

37b. What is being done by you and others that helps you to make a living?

37c. Can you identify any factors that help to maintain or improve your ability to make a living, or make it more difficult for you to earn a living? If so, what are they?

38a. Do you have the opportunity to pursue activities for self-improvement? If so, in what kind of activities, if any, do you engage? If not, why do you not have the opportunity?

Prompting questions:

- Do you have the opportunity to take any courses? If so, what type of courses, if any, are you taking? If not, why do you not have the opportunity?
- Do you have the opportunity to increase your knowledge about your kidney problem? If so, of what opportunities, if any, are you taking advantage? If not, why do you not have these opportunities?
- Have you had the opportunity to meet with any groups that help you increase your knowledge (both general knowledge and knowledge about your condition)? If so, with what groups do you meet? If not, why do you not have this opportunity?

- Do you have the opportunity to read books? If so, what type of books, if any, do you read? If not, why do you not have the opportunity to read books?
- Do you have the opportunity to watch television programs that increase your knowledge? If so, what programs do you watch? If not, why do you not have the opportunity?
- Do you have opportunities for formal and informal learning? If so, what are they? If not, why do you not have the opportunity?

38b. What is being done by you and others to increase the opportunities you have to improve yourself?

38c. Can you identify any factors that help to maintain or improve your opportunities to improve yourself, or reduce them? If so, what are they?

39a. Do you have enough free time, that is, time not devoted to work, that you can use to improve yourself and/or society? If not, why do you not have enough free time?

Prompting questions:

- About how much free time do you have each day of the week?
- What do you usually do in your free time?
- Do you d[illegible]g to improve yourself or society in your free time? If so, wh[illegible] things do you do?
- Do yo[illegible]ve enough free time to:
    1. visit with friends?
    2. take a course?
    3. belong to a voluntary association?

4. take vacations?
5. go to the theater?
6. contemplate?
7. be creative?
8. do nothing, if you so desire?

39b. What is being done by you or others to increase or maintain the amount of free time that you have?

39c. Can you identify any factors that help to increase or maintain the amount of free time that you have, or reduce it? If so, what are they?

40. How much time do you spend in a typical 24 hour day maintaining or improving your economic situation by earning a living, maintaining or improving your living and working conditions, improving yourself or society, and getting access to the things that give you pleasure?

GOODS OF THE BODY

41a. Has having a kidney problem had any effect on your sex life? If so, what?

Prompting questions:

- Has there been any change in your sexual activity since you developed your kidney problem? If so, what has changed?
- Do you have sexual intercourse as frequently now as before you developed your kidney problem?
- Do you enjoy sexual activity as much as before you developed your

kidney problem?

41b. Do you do anything special to maintain or improve your sex life? If so, what?

41c. Can you identify any factors that help to improve or maintain your sex life, or worsen it? If so, what are they?

APPENDIX 2

DEMOGRAPHIC DATA

Patient's Code Number: ____________

Sex: ____________________

Age: ____________________

Marital Status: ______________

Number of Children: ____________

Race: ____________________

Ethnic Background: ______________________

Religion: __________________________

Occupation: __________________________

Highest Educational Level Attained: ______________

Currently Employed (Yes/No): __________________

Approximate Family Income: __________________

Diagnosis: __________________________

Length of Time on Dialysis: __________________

____

Number of Admissions to Hospital in Last Year: ___________

Dates of Previous Renal Transplants, if any: ___________

APPENDIX 3

CARD SORT TASK

The questions which you have been asked are about components of the good life. These components are goods of the body, goods of the mind, goods of character, goods of personal association, economic goods, social goods, and political goods.

Here are some cards with definitions of these components of the good life. Will you please:

1) place them in an order indicating their importance to you from most important to least important, and

2) put the cards in an order indicating the amount of time you spend, if any, obtaining or enjoying each component or type of good, from most time to least time.

CARDS USED IN CARD SORT TASK

GOODS OF THE MIND ARE:

YOUR MENTAL ABILITIES, CAPABILITIES, AND PERFECTIONS, SUCH AS KNOWLEDGE, UNDERSTANDING, SOME WISDOM, CREATIVITY, INQUISITIVENESS, FEELINGS, COMMON SENSE, AND JUDGEMENT.

GOODS OF PERSONAL ASSOCIATION ARE:

YOUR FRIENDSHIPS, LOVE RELATIONSHIPS, AND FAMILY RELATIONSHIPS.

GOODS OF THE BODY ARE:

THINGS THAT RELATE TO YOUR BODILY CONDITION AND FUNCTIONING, SUCH AS HEALTH, VIGOR, VITALITY, AND PLEASURES THAT YOU OBTAIN THROUGH THE USE OF YOUR SENSES (E.G., HEARING, SEEING, TASTING, TOUCHING).

GOODS OF CHARACTER ARE:

YOUR PERSONAL MORAL CHARACTERISTICS, SUCH AS YOUR ABILITY TO DENY YOURSELF PLEASURE FOR A GOOD PURPOSE (TEMPERANCE), TO SUFFER DISCOMFORT FOR A GOOD PURPOSE (COURAGE), AND TO BE CONCERNED FOR THE WELL-BEING OF OTHERS AND YOURSELF (JUSTICE).

ECONOMIC GOODS ARE:

THOSE THINGS THAT RELATE TO YOUR LIVING AND WORKING SITUATIONS, SUCH AS BEING EMPLOYED, HAVING THE TOOLS OR EQUIPMENT NEEDED TO EARN A LIVING, HAVING FREE TIME, HAVING ACCESS TO THINGS THAT GIVE YOU PLEASURES RELATED TO THE SENSES (E.G., HEARING A SYMPHONY, TASTING A GOOD MEAL), AND HAVING ACCESS TO SUCH THINGS AS MEDICAL CARE, SCHOOLING, AND A HEALTHY ENVIRONMENT.

POLITICAL GOODS ARE:

THOSE THINGS THAT RELATE TO GOVERNMENT AND GOVERNANCE (I.E., AUTHORITY IN THE FAMILY AND OTHER GROUPS) SUCH AS PEACE, POLITICAL FREEDOM (I.E., THE RIGHT TO VOTE AS ONE CHOOSES), PROTECTION OF INDIVIDUAL FREEDOM; AND THE RIGHT TO HELP SHAPE OUTCOMES THAT AFFECT YOU AND OTHERS THROUGH PARTICIPATION IN ORGANIZATIONS AND INSTITUTIONS ESTABLISHED TO BENEFIT INDIVIDUALS AND SOCIETY.

SOCIAL GOODS ARE:

THOSE THINGS THAT RELATE TO YOUR HUMAN DIGNITY, SUCH AS EQUALITY OF TREATMENT, EQUALITY OF STATUS, AND EQUALITY OF OPPORTUNITY.

APPENDIX 4

INFORMED CONSENT FORM

Title: The Reported Quality of Life of Selected Home Hemodialysis Patients.

Investigator: Anita E. Molzahn
Master of Nursing Candidate
University of Alberta

I, ________________________, understand that:

1. the purpose of the above research project is to study the reported quality of life of the home hemodialysis patient.

2. I will be required to participate in three weekly, private, tape-recorded interviews. Each interview will be approximately one hour in length, and held at a time and place convenient to me. The content of the interviews will be transcribed (typed).

3. I may not benefit from this project.

4. my name will not appear in any written report; information obtained will be held confidential; and the tapes will be erased at the conclusion of the study.

5. I may refuse to answer any questions or may withdraw from the study at any time without jeopardizing my care.

I have been given the opportunity to ask any questions, I needed to ask and they have been answered to my satisfaction. I hereby agree to participate in the above named research project.

________________________ Signature

________________________ Date

________________________ Signature of Witness

________________________ Date

________________________ Signature of Investigator

________________________ Date

________________________ Subject Number